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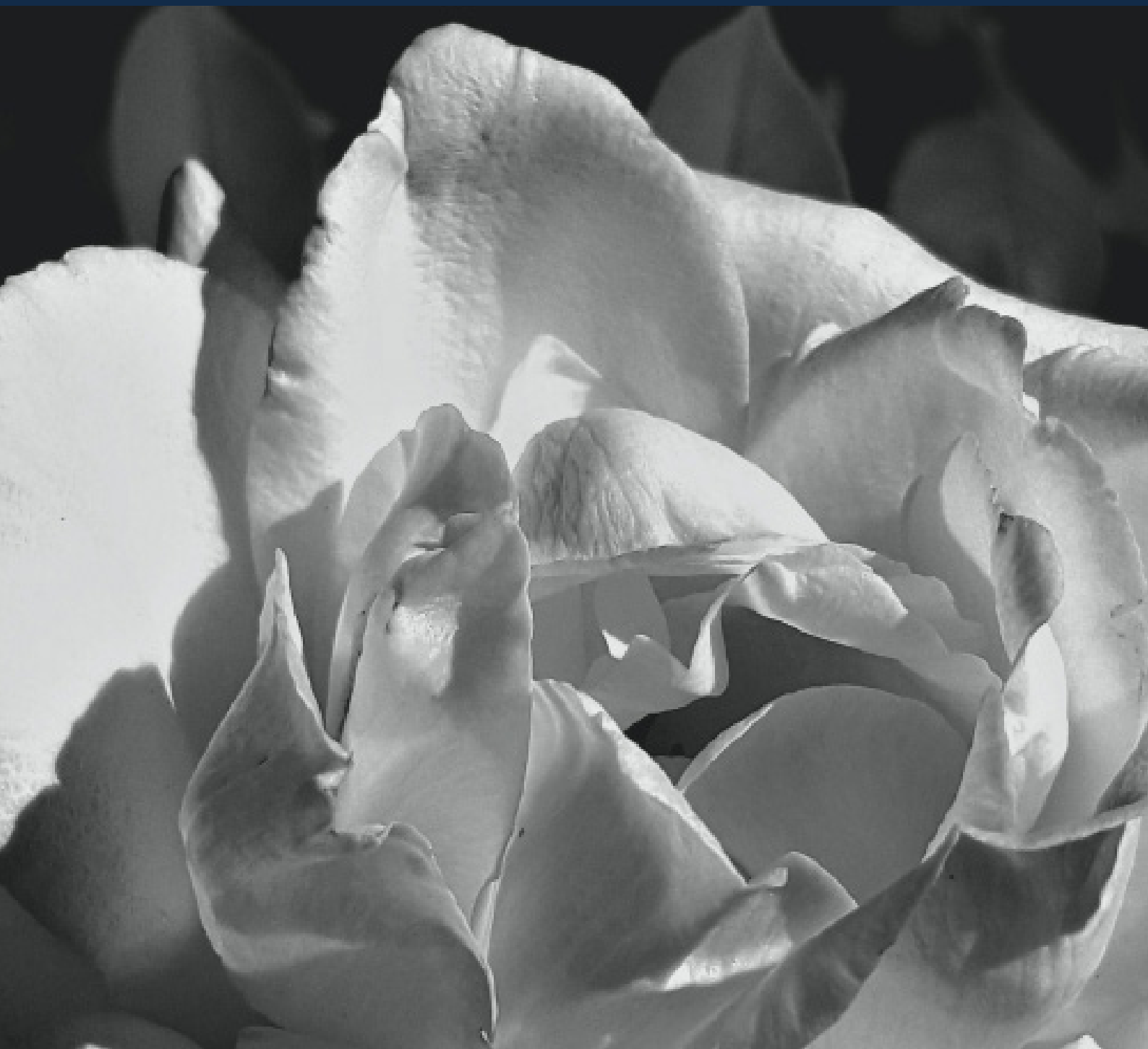
Diversity in End of Life Care

A handbook on caring for Jewish, Christian and Muslim patients



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Contents

Preface

In 2014, the D'Oyly Carte Charitable Trust generously gifted the Woolf Institute funds to develop a pilot training course on Diversity in End of Life Care.[1] This course was delivered to three hospices in the UK and designed to strengthen the knowledge of contemporary palliative care.

A three-year Rank Foundation grant and further funding from the D'Oyly Carte Charitable Trust enabled the Institute to continue providing this training course. More than 500 healthcare professionals and volunteers – working in hospices and hospitals – have benefitted from the training.

After running the courses for a number of years, we have been able to gather useful insights from them in this handbook to further support hospital and hospice staff and volunteers. This unique handbook fills a gap in teaching resources on diversity in end of life care. Funding from the above charities has made this possible and we are grateful for their generous support.

Not only will this resource supplement the Diversity in End of Life Care training days but it will also be of interest more widely to those involved in interfaith studies and end of life care.

Many contributors – all of whom are thanked in the acknowledgments – have shared their expertise, knowledge and insights into medical care and religious diversity. I would like to specially thank Helen Cornish for her unwavering support.

Finally, I remember our colleague and friend, Matthew Teather, who passed away at the Arthur Rank Hospice (Cambridge) in May 2017. May his courage and strength be an inspiration to us all.

Dr Emma Harris
On behalf of the Editorial Team

Please see page 35 for footnote information.

About this Handbook

The primary objective of this handbook is to offer healthcare professionals and volunteers some tools for awareness and the knowledge necessary for delivering effective, sensitive and appropriate end of life care to patients of Jewish, Christian and Muslim backgrounds. It aims to cover common issues, challenges and tensions that arise from the highly diverse character of those who use hospices and hospitals in the UK today.

This handbook contains a balance of practical, theological and resourceful information. It will:

- **give insights into the underlying principles and resultant practices common in end of life care in the UK; and**
- **provide a multi-faith resource outlining religious approaches, beliefs and practices towards death and dying, which may sometimes be in conflict with the secular healthcare approach.**

Improving the multi-faith literacy of those who provide end of life care in the UK today, by helping them gain a better understanding of religion and how it affects the end of life concerns of their dying patients, is like adding another important string to their bow, enabling them to administer better, more holistic end of life care.

The material is divided into distinct fields of interest and reflects a variety of circumstances where caregivers and medical experts may be present when caring for patients from different faith backgrounds. The handbook highlights some of the diverse viewpoints within each faith. The dominant faith in the UK – at least until recently – is Christianity with Islam the largest minority at 3.4m and Judaism at 340,000.[2] From a religious perspective for Jews and Muslims, what has mainly changed is that secularism has taken a much more active role. But even secularism is often informed by Christian norms.

The ‘reversion to type’ phenomenon underpins end of life care. Individuals may start this trajectory opposed to any faith view and change their opinions during illness. A person may be a secular Jew but also be uncomfortable with the traditional Christian acceptance of delayed burial. For Jews (and Muslims), quick burial (and commonly strong objection to cremation) may come to the fore.

The handbook also includes a collection of case studies, resources for further learning and a glossary of religious terms which may be unfamiliar to readers.

The content of this handbook has been informed by the tutors and participants on the Woolf Institute training programme, Diversity in End of Life Care. Our experience has shown that staff and carers benefit greatly from the knowledge acquired about the Abrahamic faiths, which, despite their significant differences, still share many commonalities.

Please see page 35 for footnote information.

3

End of Life Care in the UK

3.0 End of Life Care in the UK

The way we talk about death and the decline of quality of life that often precedes it has changed, as the world around us has changed. In the British context, these conversations are very much alive, and have taken on new levels of complexity.

Today, the UK's elderly population is more religiously diverse than at any time in our history. [Refer to Section 4.] Whilst British society has been diverse in terms of its religious, racial, linguistic and cultural makeup in the period since the Second World War, it is only in recent years that this diversity has affected palliative care in a major way.

When confronted with new levels of diversity, it is important to learn something about the particularities of each group in order to gain some practical multi-faith competency. For example, how would a patient from a particular faith background react to a given treatment plan? Knowledge about the broad principles and approaches towards end of life care and death in different faith traditions can provide carers with a helpful and reassuring awareness of diversity. Yet, while helpful, such knowledge alone is not sufficient. It may lead to unhelpful generalisations about what individuals want, bearing in mind the diversity of practice within each faith. We also need to examine our own presumptions and principles, as well as those of the institutional setting in which we work. Hospitals and hospices in the UK are places that welcome all individuals, yet they are structured around the principles and presumptions of a secular biomedical view of care and healing that is not understood by everyone.

3.1. The UK context: historical background

Although the roots of the palliative care movement can be traced back to foundations of holistic care of the dying established by 19th-century Christian religious orders,[3] Dame Cicely Saunders is considered to be the founder of the modern hospice movement. During her medical career, Saunders worked with patients and families affected by terminal cancer prognoses. In her early writings, she narrates an encounter with a dying man and recalls him saying:

> ***"I only want what is in your mind and in your heart."*** [4]

This experience and his words ignited her ambition to revolutionise the approach of the NHS to care for the dying, which did not exist as a concern in the institutional mind of health and medical services at the time.[5]

Saunders developed an approach to care and pain management centred on the concept of what she called 'total pain'.[6] It is a concept of care which reaches beyond the concern for only biomedical solutions and the alleviation of physical pain. It includes the psychological, social and, importantly, spiritual aspects of an individual's final stage of life.[7] She viewed the neglect of this broader conception of the wellbeing of the dying as more than just a question of compassion for individuals, but also as a test of the moral fibre of society as a whole.[8] Since 1967, when Saunders opened St Christopher's House – widely considered to be the first modern hospice – the hospice movement has grown dramatically.

If Saunders laid the groundwork for the development of palliative care in the subsequent decades, ethicists in the United States also contributed to what would become the pillars of medical ethics in many Western societies. In particular, the 1979 seminal publication The Principles of Biomedical Ethics by Thomas Beauchamp and James Childress was influential. Beauchamp and Childress outlined four basic principles:

- **Autonomy – an individual's right to make his or her own choice;**
- **Beneficence – the principle of acting with the best interest of the other in mind;**
- **Non-maleficence – the principle that 'above all, do no harm', as stated in the Hippocratic Oath;**
- **Justice – a concept that emphasises fairness and equality among individuals.[9]**

Please see page 35 for footnote information.

These principles have, in many respects, cemented a focus on the individual and remain central to concepts of medical ethics in the UK (and elsewhere).

Compassion is also an important element of palliative care and is a concept that is understood and practised across many religious and secular traditions.[10] Challenges remain which involve the interplay between a culturally specific and highly individualistic framework of the medical institutions in which many people pass their final days and the many diverse ways people view a 'good death'.[11]

In an article discussing the future of palliative care, Saunders emphasised the need to recognise the spiritual and existential issues of patients and families from diverse backgrounds. It is important to address the discrepancies between these and our current understandings of medical care as she noted:

"Our common humanity demands no less." [12]

3.2. The UK context: guiding principles of end of life care

When considering end of life care in particular, the UK General Medical Council (GMC) has elaborated a set of guiding principles[13] which are summarised below. These are presented as universal principles, applicable to all dying people and their loved ones. There may be some friction and even conflict between these principles and the beliefs and practices of people of different faith traditions and cultural backgrounds. It should, however, be noted that all of these principles allow for a number of interpretations that include, or go beyond, the concern of multi-faith care.

According to the GMC, the following ethical principles should be respected by medical practitioners working in the field of end of life care:

3.2.1. Equality and human rights

All patients, regardless of identity or disability, and their close ones must be treated fairly and with dignity, respect and compassion, as well as be afforded the right to privacy and confidentiality.

While these values are generally accepted by many in Western society, there are instances in which they can conflict with approaches and the circumstances of care among different religious and cultural groups in a multi-faith context. For example, the personal focus on capability and individuality – maintained in the concept of human rights – may be challenged by the value placed by the faith community on the position of family members and religious leaders in patient decision-making. The idea of the individual's autonomy in such a setting may not be accepted and decision-making may be guided and negotiated by different norms and practices. In terms of privacy and confidentiality, family and religious figures may not agree with healthcare workers' expectations of sharing privileged or intimate data.

3.2.2. Presumption in favour of prolonging life

Decisions concerning potentially life-prolonging treatment must not be motivated by a desire to bring about the patient's death, and this presumption normally requires that you take all reasonable steps to prolong a patient's life.

It is important to keep in mind that the caregivers' and the patients' understandings of what constitutes 'a desire to bring about death' or 'reasonable steps to prolong life' might be communicated in different ways. Sometimes religious principles and their individual understanding may come into friction with this presumption, such as religious prescriptions on invasive treatment deemed unnecessary or excessive, or a patient's own desire not to prolong their life artificially in the light of a terminal prognosis.

3.2.3. Presumption of maximising decision-making capacity

Caregivers must work on the presumption that every adult patient has the capacity to make decisions about their care and treatment. It should not be assumed that a patient lacks the capacity for decision-making because of their age, disability, appearance, behaviour, mental condition, beliefs, apparent inability to communicate, or because the decision seems at odds with generally accepted wisdom or the wishes of their relatives.

In this principle, the focus on the individual is again present. It might come into friction with norms and practices regarding the intervention of family or religious figures in medical decision-making. For example, a familial, cultural or faith-informed circumstance may involve a patient being shielded from knowing the details of their prognosis, or otherwise kept from receiving certain information. This practice would seem at odds with the institutional understanding of informed consent and decision-making capacity.

Please see page 35 for footnote information.

4

Demographics of End of Life Care in the UK

4.0 Demographics of End of Life Care in the UK

It is a challenge to attain accurate statistics about the elderly that consider the relationship between faith and particular needs during end of life care. The UK's most comprehensive primary data, the 10-year Census,[14] keeps the question of one's religion as optional self-identification. As many care professionals know, religion and God can suddenly matter to the dying, even if it has never seemed to mean much in the prime of a person's life.

The office for National Statistics (ONS) and other surveys suggest that the UK population will continue to grow and become more ethnically diverse. It is, therefore, essential that caregivers and medical professionals make end of life care more accessible and responsive to the country's multi-faith reality.

4.1. A growing elderly population

In mid-2018, there was an estimated UK population of 66.4 million and migration remained the main driver to population growth. The ONS recorded that, by 2018, around 18.3% of the UK population were aged 65 years or over (compared to 15.9% ten years earlier).[15] The ONS has projected that, by 2038, 24.2% will be aged 65 years or over.[16] According to Sarah Coates, Centre for Ageing and Demography (ONS):

The structure of the UK's population is changing: people living longer and having fewer children means the age structure is shifting towards later ages.[17]

4.2. An increasingly diverse elderly population

Today, there are higher proportions of citizens with a recent migrant history to the UK from both EU and non-EU countries; this has resulted in greater diversity, especially in metropolitan areas. So, in addition to having a growing elderly population more generally, the cultural and religious diversity of the UK's elderly has also increased.

4.2.1. Jewish elderly population

In 2018, the ONS produced data available from the Annual Population Survey (APS) at the Great Britain level (England, Scotland and Wales). The Jewish population numbers around 340,000.[18] Jews are older than the general population; the Institute for Jewish Policy Research (JPR) commented, in 2011, that 12.4% are 75+, compared with 7.5% generally.[19]

Compared to other faith communities, the British Jewish community has several care homes and hospices, and there are some well-established facilities for provision of palliative care. However, this does not mean that all Jewish patients are supported by their own faith institutions, as many care staff will already be aware. Jewish patients often have a strong desire to be connected with long-established Jewish customs and practices related to the final stages of life.

4.2.2. Christian elderly population

The 2011 UK census counted 33.2 million people who identified as Christian,[20] over one in five were aged 65 or over.[21] Measuring the elderly by church attendance is less accurate, but most studies find that the typical age of church attendees is around 50 years old. Church attendance proportions vary across denominations and also geographically across the different regions of the country.[22] Most studies have reported that around 1 million people regularly attend Sunday services. However, nearly three times that number attend a Christmas service, and a great many more use the church for other services, such as baptisms, marriages and funerals.

These figures provide little real measure of how important faith becomes at the end of life. It is still important to connect with patients in care even if they are identified as culturally rather than actively practising Christians, in order to better understand the connection that the individual feels with their Christian heritage and traditions.

4.2.3. Muslim elderly population

In 2011, only 4% of Britain's Muslims were aged 65+. This accounts for over 100,000 people. This figure is rapidly rising and is expected to almost double again by the census in 2021 to 190,000.[23] By 2031, the number of Muslims in the UK aged 65+ is expected to reach 250,000.

The average age profile for Muslims is significantly younger than the national average. However, this can mask an emergent ageing Muslim population, of whom 326,000 are aged 50+ and represent 1.7% of the UK's 50+ population, as well as 12.1% of the entire British Muslim population. When we consider that (1) the younger average age will yield a faster than average rise in Muslims aged 50+ and (2) the uneven geographic spread of Muslim residency, which means that Muslims can make up a significant proportion of the local population in certain areas,[24] we can see a growing need for advance care planning services. This is especially the case in some local authority areas, including about 70 local residential ward areas that have a Muslim population of 40% or greater.

Please see page 35 for footnote information.

5

Understanding Diverse Faith Perspectives

5.0 Understanding Diverse Faith Perspectives

The Abrahamic faiths all believe in one God. However, there are different understandings about God and the implications of believing in God, both between different faiths and within each faith. It is important to keep in mind that all faith traditions contain a significant level of internal diversity, as witnessed by the existence of sub-groups, sects, denominations or schools of thought. People, who adhere to, or identify with, Judaism, Christianity and Islam, exhibit varying degrees of doctrinal orthodoxy, as well as cultural and ethnic diversity. This plurality makes 'one-size-fits-all' descriptions or rules difficult, if not impossible, to determine.

This section offers some general points about the respective religious perspectives around death and end of life, but the information given here is by no means comprehensive because members of faith communities differ among themselves. As a guiding principle, it is best to approach care on a case-by-case basis and remain attentive to, and considerate of, the desires and requests of individual patients and their circumstances.

Carers who have access to religious authority figures through chaplaincy services, or others with knowledge of traditional norms and practices, have found the support immensely valuable as a means of improving their understanding of their patients. Many care staff we consulted have spoken about erring on the side of caution and hesitating to act to avoid causing any distress. Others have said how they trusted their instincts, but later discovered that they may have managed situations differently to better comply with religious teachings.

5.1. What is important to people of faith towards the end of life?

The end of life phase represents a final and inevitable journey for an individual. However, unlike most of life's other phases, a person may have little to no control over its duration or its character. Other phases may be measured by years and by key stages, or perhaps by the fruits of paths followed and turns taken marked by growth spans or successes and failures. In the end of life phase, so much may feel inevitable for an individual and so many of life's rules and metrics change, as their body slows down, showing signs of decline and deterioration.

Carers need to be aware of their own faith feelings, concerns and objections, and avoid promoting their own views on patients or their families. This applies also to a secular carer who may inadvertently not take faith into account.

Please see page 35 for footnote information.

Carers also need to be aware that people of faith and those of no faith share many similar desires at the end of life. A person may belong to a community and desire the rituals and customs of the particular community at the end of life, but even here, there is an irreducible, unique, personal element to which carers need to be attentive. In addition, individuals who consider themselves as having 'no faith' may still hold deeply held beliefs that are important to them. It is worth noting that a patient (and/or their family) may prefer a carer from their own faith perspective.

People who belong to identified faith groups with particular faith traditions may include individuals who 'don't really believe in' certain elements, but do 'personally believe in' others. These 'dos and don'ts' may not be found in a standard textbook. Similarly, people of 'no faith' rarely believe in nothing and may hold onto aspects of their life in ways that may resemble religious beliefs. It is useful to note that this personal aspect of faith and belief can be as important for patients in end of life care as official doctrine or religious laws mediated by religious authority figures. Care professionals and volunteers might instinctively recognise this through their experience of working with a range of individuals from different faith traditions and social backgrounds. Yet, it remains helpful and reassuring to understand key characteristics of different faith traditions.

5.2. Common threads in the Abrahamic family of faiths

The Abrahamic family of faiths teaches that life is a gift from God, over which God ultimately maintains sovereignty; a person's life and being continue after earthly life and death is described not as a final end but as a passage or a transition from one form of existence to another. This existence, after earthly death, is sometimes spoken of as the 'afterlife'.[25] All three faiths believe that everyone's life will be subject to judgement by God. This belief can have a powerful impact on people of faith, an impact that varies considerably from person to person, but which can range from feeling calm, comforted and at ease, to feelings of worry, guilt and fear.

Interwoven with the belief in an afterlife is the teaching, in all Abrahamic faiths, that the human person is not merely the material body but is the union of both body and soul. The soul or spirit, which in all three traditions is understood as the direct, enlivening 'breath' of God, means that every human life is of sacred value and a gift from God. In the Abrahamic faiths, therefore, death is often framed as the parting of the soul from the body[26] – and the body is believed to undergo a 'renewal' in the final resurrection.

It is important for people of faith to address matters related to their death in accordance with their faith teachings about God, the 'afterlife' and divine judgement. Some people will seek to atone for sins committed in an earlier phase of life. Others will be concerned with getting the most out of their current phase of life in religious, spiritual or personal terms. Still others will concentrate on the stage to come, death itself and compliance with religious teachings, traditions or accepted protocol.

When we discuss Judaism, Christianity or Islam or, in fact, any other religious or philosophical tradition, there is tremendous diversity of belief and practice – different schools of thought, interpretations of religious texts and religious law and degrees of religious practice.

This means it is not possible to reduce this complexity to a level where we can simply say a Jew, a Christian or a Muslim will follow a particular approach or agree to certain medical procedures at the end of their life.

The next three sections will introduce readers to certain basic principles within each faith, which inform decision-making. It should be noted here that, throughout the handbook, readers will notice the diverse views within each faith regarding belief and practice.

5.3. Judaism and Jewish patients

The UK Jewish community includes a diverse range of religious and cultural affiliations. There are strictly Orthodox (some of which belong to Hassidic movements), mainstream or 'modern' Orthodox, Masorti (or Conservative), Reform and Liberal Jews, all with their own respective faith organisations. There are also many secular Jews and those with no religious affiliation. The main representative body is the Board of Deputies of British Jews.[27]

In Judaism, Halachah refers to Jewish law which guides everyday life. Included are religious teachings and applications which relate to a range of issues surrounding end of life care. These may be interpreted strictly or more loosely depending on the individual's level of religious affiliation.

The obligation to save life *(pikuach nefesh)* underlies all religious approaches to medical ethics, as does the obligation to heal.[28] Jews do not see themselves as the owners of their bodies, but 'God loans them to us for the duration of our lives, and they are returned to God when we die'.[29] This can have significant implications in patient decision-making and treatment plans for Jewish patients interacting with secular medical institutions.

Visiting the sick *(bikur cholim)* is a Jewish obligation of Biblical origin. As Dr J.S. Katz notes, this duty prevents 'the alienation and isolation of the sick as well as to pray for their complete recovery *(refuah shlaimah)*'.[30]

It is important to recognise that, in orthodox circles within Judaism (and in Islam too), there are customs around gender relations that might result in the patient's rejection of being attended to by any medical professional of the opposite sex. [Refer to Case Study 7, page 31]

Orthodox Jewish patients might not be able to make appointments or undergo certain procedures on the Sabbath (which begins on Friday about one hour before nightfall or 15 minutes before dusk and ends on Saturday at nightfall). [Refer to Case Study 11, page 33.] Consideration should equally be made for religious holidays (as in Islam) that might not align with the typical Christian-centric dates that structure the civil calendar in the UK.[31]

In a Jew's final moments, the recitation of prayers including the daily declaration of faith *(Shema)* and the practice of confession *(Viduy)* are important as, indeed, are similar devotions in Christianity and Islam. This act might involve the presence of a rabbi, as well as family and community members. [Family intervention is discussed further in Section 6.2.]

Jewish and Islamic law outline specific prescriptions for the treatment of the deceased, including honouring the dead, treating the body with respect and care from death until an expedient burial within 24 hours. Whilst also recommending the expediency of a funeral, a family's request to wait for those who have to travel from afar will be taken into account in Reform and Liberal Judaism. In the UK, most Orthodox communities permit brief delays in burial to allow key family members to arrive (e.g. overnight) as not infringing on honouring the dead *(kavod hamet)*. There are also prohibitions on cremation although some branches of Judaism permit it.[32] In orthodoxy, post-mortem examinations are actively discouraged to ensure as little interference with the body as possible. However, non-invasive procedures such as CT or MRI scans may be considered acceptable.

Please see page 35 for footnote information.

5.4. Christianity and Christian patients

It may seem strange to suggest the need to increase staff knowledge of Christian teachings in the UK. However, as many experienced carers will readily testify, assumptions and generalisations can easily be made that negatively impact on patient care. Increasingly, there is also unfamiliarity with the beliefs and practices of new churches, as well as ignorance in secular society of basic Christian teachings and practices.

Some caregivers have spoken of drawing from their own experience, tradition and family rather than connecting to the patient's beliefs. This has been due to a lack of understanding or awareness about different Christian denominations. Carers also described events surrounding ethical dilemmas when treatment programmes were disrupted or challenged by family members who called upon divine interventions for healing and comfort, an experience most often linked to Evangelical or Pentecostal groups.

As in all Abrahamic faiths, Christians believe life to be a sacred gift from God and that each life has intrinsic worth and dignity that must be respected. This belief may, at times, raise questions about when it is ethically right to withhold or withdraw treatment. The palliative care approach, with its whole person holistic care vision, grew out of a Christian environment. This approach seeks to identify and care for the physical, psychological, social and spiritual needs of dying people and their loved ones.

The core of Christian faith – believing in and accepting the death and resurrection of Jesus – will be important for the decisions individual Christians make at the end of life as they consider reconciliation with, and salvation of, God and the promise of the afterlife. Most Christians wish to know the facts about their medical condition and to be given correct and sufficient information by healthcare providers, so that they can make informed decisions about their care and also to prepare for death.

For many Christians, it is important to engage in self-examination, repentance and confession before dying. Some wish to be as conscious as possible at the moment of death, which might have implications for the palliative medicine given. Analgesics or other medical interventions affect the consciousness of the patient. Others are content to be sedated and to entrust themselves to God through such medical care; this will also depend on their condition near the time of death.

Many Christians, like Jews and Muslims, will also appreciate the presence of their minister or other religious authority to perform various end of life rites. These include Prayers for the Sick, Prayers for the Dying, Confession and bodily Anointings, Prayers of Commendations to God or the Eucharistic rite.[33] Through prayers and the consumption of bread and wine, Christians believe themselves to be united to Jesus Christ in his death and resurrection.[34]

5.5. Islam and Muslim patients

Islam is not a monolith, but a mosaic comprising a diverse community of believers. As is the case for British Jewry and Christianity, there is a wide range of internal diversity among British Muslims, with numerous denominations and schools of thought.[35] However, there are some basic tenets of Islamic ethics in regard to medical care.

For Muslims, end of life decisions and ethical guidance are considered in accordance with the sacred law of Islam *(Shari'a)*. Islamic medical ethics uphold the obligation to save and prolong life, but also the importance of limiting unnecessary life-sustaining treatment. This continues to be the subject of debate among Islamic scholars and medical ethicists.[36]

For Muslims, as for Jews and Christians, life is a sacred gift from God, and God has sovereignty as the Giver and Taker of life. Muslims view themselves as 'stewards' or caretakers of their bodies[37] and enact their autonomy or self-will with the will of God in mind – acting for His pleasure. The Muslim medical ethicist Abdulaziz Sachedina noted:

> ***"As caretakers, human beings are charged with taking all the necessary steps to preserve their body in a way that will assist them in seeking the good of both this world and the next." [38]***

Muslim patients might look to family and religious authorities to guide them in decisions regarding treatment plans and end of life rituals. It is advisable to involve the chaplaincy services whenever possible.

In Islam, as in Judaism, there are customs around gender relations that might result in the patient's dissatisfaction with, or even rejection of, being attended by healthcare professionals of the opposite sex.

As with Jewish patients, considerations should be given where Islamic religious holidays might not align themselves with the largely Christian-based nature of the civil calendar in the UK.[39] Muslims pray five times a day. Fridays, however, are considered as the dedicated day of worship when the most important prayer of the week, the *Jum'a* (congregational prayer) is performed.

As Muslims approach death, they may be encouraged by relatives or religious authority figures to recite the declaration of faith *(Shahada)*.[40] If possible, the patient is turned to face toward Mecca. Depending on the orientation of the bed in the room, visitors present may move or rearrange the furniture. [Refer to 6.2. Family Intervention.]

There are formal rulings in Islam (Fatwas) which pertain to the treatment of the deceased. Likewise in Judaism, these include the expediency of funerary and burial rites within 24 hours and prohibitions against the practice of embalming, autopsy and cremation. Post-mortem examinations of the deceased may be acceptable in certain circumstances, but some Muslims might strongly protest against these practices. The majority of Islamic scholars consider organ donation to be acceptable. Despite this, conversations with families may be challenging, as there are differences of opinion amongst scholars and within the community.[41]

6

Aspects of End of Life Care

6.0 Aspects of End of Life Care

A review of case studies from hospitals and hospices across the UK has enabled us to define four primary themes in end of life care in a multi-faith context: the concept of advance care; family intervention; the patient-caregiver relationship and communication; and concerns after death. In this section, we use these themes to organise the caregivers and medical practitioners' experiences while caring for patients of diverse backgrounds.

6.1. Advance care planning

Depending on the cultural and faith background and individual experiences of the patient and their relatives, several issues might arise during advance care planning. These include divergent or disparate understandings of the concept of advance care itself, the acceptance of mortality, advance directives and the withholding of, or withdrawal from, treatment.

6.1.1. Concept of advance care, the acceptance of mortality and advance directives

The concepts of advance care, acceptance of mortality and advance directives are difficult for all patients given a terminal diagnosis.

Occasions might arise in which patients and their relatives have highly emotional and sometimes hysterical reactions to the prognosis of terminal illness, the failure of treatment or the imminence of death. It is important to consider that such reactions are not necessarily related to the patient's religious beliefs or perspectives. Such situations might benefit from the intervention of chaplaincy services to help patients and their relatives make sense of, and come to terms with, the diagnosis. [Refer to Case Study 1, Case Study 2, page 29 and Case Study 10, page 32]

Some patients might refuse or significantly delay planning for death. This can lead to situations in which appropriate funerary, burial or other religious preparations have not been made and social networks not activated. (For example communal networks, local religious authorities and other family members etc. have not been informed). There have also been cases where patients have refused treatment in the expectation of a miracle or other divine intervention and healing ('God will heal me'). For example, some Evangelical Christian patients have insisted on waiting for divine healing because they feel that they have lived pious and good lives and, therefore, do not accept their medical prognosis. In some cases, this has resulted in a refusal to make contingency plans for the care of young children who will survive the patient. In some Muslim households too, particularly those of a South Asian background, the spiritual and practical guidance (and healing) of a *pir*[42] is often sought in the event of a sudden misfortune or serious illness.

Lasting Power of Attorney (LPA) allows an individual to appoint another to make decisions for them in the event that they lose capacity.[43] An LPA for health and welfare allows for decisions about daily routine, medical care and living arrangements.[44] The LPA will provide instructions about refusing or consenting to treatment unless the individual has made an Advance Decision to Refuse Treatment (Living Will) after appointing their LPA. A Living Will completed before the LPA is appointed can be overridden.

The drafting of a Living Will by patients – a legally binding written statement detailing wishes for future medical treatment and religious rites after death – has helped medical professionals to mediate difficult situations. For example, some Muslim converts might wish their body to be treated in accordance with Islamic customs, but after death their non-Muslim family do not honour these wishes.

6.1.2. Palliative sedation

Palliative sedation – previously known as terminal sedation or controlled sedation – is the practice of giving sedative drugs in the last few days or hours of life to dying patients with unrelieved severe symptoms of pain and agitation, until coma develops and lasts until the individual dies. Once the person is comatose, artificial nutrition and hydration are usually withdrawn.

This practice is controversial because it makes an individual unconscious and raises questions about hastening death. In addition, difficulties arise from disagreements around the place of nutrition and hydration at the end of life. While this is a medical question, it can be very difficult for loved ones to accept the withdrawal of nutrition and hydration, for these are what sustain life. As there are different views about what is actually helpful to the dying person and what is best remains controversial, most people would probably prefer that these are continued. Unsurprisingly, withdrawing nutrition and hydration can lead to an accusation of hastening death. Guidelines written by The National Institute for Health and Care Excellence (NICE) advocate a continuing review of nutrition and hydration in patients nearing death with the patient, where possible, or their loved ones.[45]

Please see page 36 for footnote information.

The 'More Care, Less Pathway' Report (2013) makes the normative nutrition and hydration situation very clear:

> ***"There can be no clinical justification for denying a drink to a dying patient who wants one, unless doing so would cause them distress. The urge to drink when thirsty is very powerful and basic. Good mouth care if the patient simply has a dry mouth may well be sufficient, but to deny a drink to a thirsty patient is distressing and inhumane."*** [46]

In Judaism, the withdrawal of hydration and nutrition can be viewed 'as active euthanasia because of the inevitability of death'[47] although, as with Islamic rulings, each situation must be considered as it arises.[48]

Some Christians will wish to be as conscious as possible at their death, so as to be able to live their death consciously as a passage to God, in union with Jesus Christ and his self-offering to the Father; others will be content to surrender themselves to God's loving care through the appropriate medical processes, including palliative sedation. Christians are able to accept the withdrawal of nutrition and hydration in cases where it is clear that it is best practice to do so.

6.1.3. Withholding of, or withdrawal from, treatment, euthanasia and suicide

When considering treatment plans and pain medication, people of faith will often consult with religious authority figures when making decisions. While administering medicines for controlling pain may be permitted, the unnecessary prolonging of the dying process can be a sensitive subject in Jewish, Christian and Islamic medical ethics.[49] For Muslim, Jewish and most Christian patients, suicide is forbidden. Finding an acceptable balance between unnecessarily prolonging life and prematurely ending it, may make treatment decisions and the provision of pain medicine a complex task.

6.1.3.1. Withholding of, and withdrawal from, treatment

The withholding of, and withdrawal from, treatment are usually considered medical interventions about which patients and families will deliberate. Negotiations about pain relief are usually classified as separate to this deliberation.[50]

As previously mentioned, in Judaism, the obligation to save life *(pikuach nefesh)* replaces almost all other responsibilities. In his seminal book, Dangerous Disease and Dangerous Therapy, Rabbi Akiva Tatz explains, from the Orthodox perspective, that:

> ***"A dangerously ill patient must be aggressively treated, desecrating the Sabbath and transgressing almost all other prohibitions if necessary. Even where there is no known definitive therapy, whatever can be done for the patient must be done both to prolong life and improve its quality; and even where it is clear that no medical therapy will help, the patient must not be abandoned."*** [51]

In Liberal and Reform denominations, there is broad respect for individual autonomy in decision-making, including the right to refuse care if the patient feels it would not be effective or would be too painful.

Tatz describes two categories of terminal illness – *chayei sha'a* and *goses*;[52] the former refers to a terminal situation in which death is likely in the near future (i.e. in about a year[53]) whereas the latter describes imminent death (i.e. within three days). However, 'three days' cannot be assumed of any patient given today's technology.[54] Others such as Elliot N. Dorff clarify the state of *goses* more flexibly to describe a patient 'who will live up to a year a more, or in terms of symptoms rather than time and they then apply the permission to withhold or withdraw machines and drugs more broadly'.[55]

Rabbi J. David Bleich comments on the withdrawal of treatment from a *goses*:

> ***"Needless to say, it is self-evident that if the goses can be restored to good health, or even if the state of gesiah can be reversed, the obligation of pikuach nefesh mandates that the requisite medical intervention be instituted. It is also clear that there exists many patients who, in the past, would have been described as gosesim but who today can be treated."*** [56]

Even in situations where it is permissible to withhold or withdraw therapy,[57] Tatz argues that:

> ***"Basic staple needs must always be provided. A patient may never be starved or dehydrated to death, no matter what the clinical situation."*** [58]

Please see page 36 for footnote information.

As already explained, there are different approaches within the various strands of Judaism which may seem bewildering. It is, therefore, good practice to consult a rabbinic authority in certain circumstances.[59] What is important to understand is that there is a very strong emphasis in Judaism on saving and preserving life even if interpreted in different ways resulting in different decisions being made.

It has been reported that some Pentecostal Christian patients have refused pain medication to feel some level of suffering as self-punishment for sinful behaviour, or to emulate the divine suffering that, in some forms of Christianity, is intimately linked to notions of devotion and salvation. Other Christians may also link the sufferings they experience to those of Christ in his suffering. Muslims, too, see the pain experienced at the end of life as 'expiatory' and as a way of lessening their pain after death. [Refer to Case Study3, page 29.]

6.1.3.2. Euthanasia

Euthanasia, 'assisted dying' or assisted suicide is the deliberate bringing about of an individual's death by another or themselves with help, for the sake of the individual, because this is thought to be in their best interest.

The euthanasia debate attracts attention worldwide. Discussions range from the dangers of misuse to the effect on medical relationships and the continued development of palliative care. In the UK, assisted suicide and euthanasia are presently illegal, but in some European countries, Canada, Columbia, Victoria in Australia and a number of American states, it is permitted in specified circumstances.

The Abrahamic faiths believe – as do other religions – that all human life is sacred and, therefore, reject euthanasia as the sixth commandment states:

"You must not commit murder"
(Exodus 20:13)

In Judaism, rabbinic authorities forbid euthanasia. Jewish law stipulates that it is even forbidden to 'help' a patient who is expected to die within 72 hours *(goses)*, even if they are in extreme pain and very close to death. This would be considered as murder. However, views are changing. Commenting from the perspective of Reform Judaism, Rabbi Dr Jonathan Romain noted in 2017:

"The first of these objections [to active euthanasia] was pastoral, based on concerns that abuse could take place if a change in the law is enacted… The other objection was theological, related to notions of the sanctity of life – a gift of God that is to be valued above all else. We in IFDiD [Inter-faith leaders for Dignity in Dying] agree that life is sacred, but in our congregational work, we have seen too many people die in great pain who should have been allowed to pass away earlier, as they had wished. That, too, is part of valuing them." [60]

Christians, Jews and Muslims regard life as a gift from God, which only God may end. Human beings are created in God's image and are in a relationship with God and each other. Being created in God's image gives intrinsic value and worth to every human being, whatever their physical and psychological condition. No human life is ever worthless.

In Islam, a hadith[61] affirms that God created Adam 'in His image', and this is often cited as a testament to the sacrosanct value of human life. Islam forbids euthanasia. God gives life and chooses when an individual will die. The Qur'an states:

"And no person can ever die except by Allah's leave and at an appointed term"
(3:145)

Birth and death are part of that gift and to be fully lived, like any other part of life: to cut off the ending of life might be to lose out on the mysterious gifts dying enshrines. This does not, in any way, imply that palliative pain relief should not be given – the palliative care movement, seeking the good management of an individual's 'total pain' and the holistic care of their physical, psychological, spiritual and social needs, grew out of a Christian perspective – but pain relief should not deliberately aim to hasten someone's death, only to relieve pain. Nor does it mean that exceptional treatment methods need to be used to keep people alive against their will.

Please see page 36 for footnote information.

While Christians highly value personal autonomy, it is not an absolute value. Christians live as individuals in families and societies and their choices and actions inevitably have an effect on others: their autonomy is lived in relation with, and to, others and choices made with regard to mutual responsibilities to each other.

These views are held by most practising Christians. Yet there are also some Christians (as well as some Reform and Liberal Jews) who support the practice of euthanasia. They argue that:

- **Helping to end a dying individual's pain is part of the love and compassion involved in fulfilling Jesus' command to 'love your neighbour as yourself';**
- **Autonomy and the right to choose is part of God's gift of life and that this includes the right of individuals to decide when to end their own life and hand themselves gratefully back to God;**
- **Individuals have the right to choose a peaceful and dignified death for themselves.**

6.1.3.3. Suicide

The Abrahamic faiths believe that it is sinful to commit suicide and religious authorities are rigid in the view, especially as it conflicts with the fundamental value of preserving human life.

In Islam, some authorities indicate that Muslims are only held accountable for sins committed in a sound state of mind. Whether an individual was of sound mind at the point of suicide, only God can judge and either punish or forgive. In Judaism too, if it is possible that another factor is at play:

"Such as extremes of fear, pain, distress or mental illness, then it's almost as though this person were 'coerced' into suicide, and it's not considered a suicide of clear and sound mind." [62]

When a person commits suicide, this is clearly a time of severe distress for them and their family and friends, which can increase when funeral arrangements are made. In Judaism and Islam, some religious authorities will not perform a religious funeral service. Those making the funeral arrangements may need to be supported by the funeral director in relation to the service and may also need or wish for personal support from their religious leader or chaplaincy. Liberal and Reform Judaism will consider performing a burial or cremation in accordance with Jewish tradition.

Traditionally, suicide has been regarded by Christians as a very grave sin, against God who gives life and who alone can end a life. The act cuts off all possibility of human flourishing and growth. It is also against the community, whom it harms by the distress it causes through neglecting one's responsibilities to others. Traditionally and until quite recently, people who committed suicide were not allowed to be buried in consecrated ground (space blessed and set aside for the burial of Christians) nor were any Christian funeral rites permitted for them.

More recently, there has been a softening of attitudes. This is probably linked, on the one hand, to the development of the human sciences, especially psychology, which recognises the multiple sources of human action and emotion and the complexity of attributing culpability. On the other hand, attitudes have been affected by a more pluralistic society, where individual context, outlook and choice is more highlighted and accepted. While traditional Christian churches retain the conviction that suicide is a sin, there is more emphasis on God's mercy and of leaving all judgment to God who judges justly. With this change of emphasis, people who commit suicide are generally allowed to be buried in Christian burial sites and receive Christian funeral rites, although it is sometimes a cause of controversy.

6.2. Family intervention

Intervention by family members or other significant figures play an important role in a patient's end of life care. While the presence of family is generally helpful, desired and emotionally and spiritually essential during end of life care, some problematic situations can arise. The key issue is one of communication and trust between the family and the healthcare team.

Misunderstandings may arise between caregivers and relatives regarding, e.g., the nature of intervention in a patient's decisions, communication with medical staff and post-mortem wishes. It has been reported that many Muslim and Orthodox Jewish patients' families have discouraged the medical staff from sharing essential information regarding a terminal prognosis with the patient and insist on only sharing positive news.

Cases have been reported in which relatives present have insisted on continued treatment options, even if they were invasive and otherwise discomforting to the patient. This includes insistence on artificial hydration and nutrition, even when it is a risk to the patient's condition or cause of greater pain and hardship.

Please see page 36 for footnote information.

Relational autonomy is increasingly recognised within healthcare practice and is central in end of life care. However, some suggest that it can also appear to deny individual autonomy. Family intervention can be manifested in various ways. Visiting hours and number of permitted visitors may prove difficult. For Muslim patients, several family and community members will join the patient for visits and prayers. This may necessitate practical and space requirements and adaptations within the hospital or hospice setting and practices. [Refer to Case Study 5, page 30 and Case Study 6, page 31.]

It is important to note that some strictly observant Muslims pray 5 times a day, and Jews three times a day. Visitors may wish to pray in another room close to their loved one. Families may insist on performing certain rites close to, and following, death. For example, in traditional Jewish practice, the deceased's body should not be left alone after death (although it is recognised that climate conditions [excess heat] may make this impossible). Family and/or communities will be appointed to sit with the body (usually on a rota, so access at night is required) and recite Psalms until burial takes place. [Also refer to Section 6.4.2.]

6.3. Patient-caregiver relationship and communication

6.3.1. Language barriers and translation challenges

General misunderstandings can occur because of language and translation barriers, but these may also be linked to the nature of medical treatment in health care environments. Cases have been reported in which staff requested moving a patient from the home to a hospital for care, which precipitated worries and panic based on the misunderstanding that the need for hospital care signalled the imminence of death.

Family members and patients may communicate in a language other than English, a language not understood by healthcare staff, while refusing to translate or keep staff aware of things that might be important medically or relevant for the treatment plan. Within the Muslim communities, a broad range of first languages or mother tongues may be spoken (such as Arabic, Punjabi, Urdu and others); for some strictly Orthodox Jews, Yiddish may be the main language.

In other situations, a patient may request an interpreter who is not a member of their family, in order to speak confidentially with the medical staff about their treatment or condition.

It is important to keep in mind that, while decision-making practices involving family and religious figures might have certain faith-based characteristics, such issues are not necessarily attributable to religion or culture and might simply express the character of a particular family dynamic. [Refer to Case Study 5, page 30.]

6.3.2. Culturally specific gender relations

Many Muslims and Orthodox Jews observe certain customs regarding gender relations, especially with regards to physical contact. This can sometimes create a barrier and potential discomfort for staff for whom physical touch is a normal and assumed aspect of care and expression of sympathy. It is important to bear in mind that, if their patients are Muslim or Orthodox Jews, it might be inappropriate for female caregivers to engage in either skin-to-skin contact or one-to-one consultations with male patients, and vice versa. [Refer to Case Study 7, page 31 and Case Study 8, page 32.]

6.4. Concerns after death

For other details related to religious laws pertaining to concerns after death particularly in Judaism and Islam, refer to Section 5.

6.4.1. Death certificates and post-mortem examinations

In the UK, a death certificate is legally required stating the cause and date of death of a person. For Muslim and Jewish patients in particular, it is important to speed up the process of acquiring the death certificate to ensure the religiously required early burial is not delayed. In cases of death by uncertain causes in which a coroner must be involved in issuing the certificate, it is important that this should be done as quickly as possible. [Refer to Case Study 9, page 32.]

Although it is not always required, post-mortem examinations or autopsies by a coroner may sometimes need to be performed where the cause of death is not evident, or where there is a suspicion that the patient died due to unnatural causes. Certain non-invasive examinations, such as MRI or CT scans, do not necessarily violate Jewish or Islamic religious laws pertaining to the treatment of the body. However, the technological infrastructure for such scans might not be available. If an autopsy is required, this can be very distressing for all families, whether they are religious or not, but in the case of Jewish and Muslim patients, there is additional distress, both because it is considered an unlawful defilement of the body and because it may delay burial. [Refer to Case Study 12, page 33.]

Please see page 36 for footnote information.

6.4.2. Dignity of the dead (customs following death and organ/tissue donations)
Judaism, Islam and some Christian groups have prescriptions and customs involving the washing or other preparations of the body after death. For Jews and Muslims, such practices are typically performed shortly after death by a religious figure, but might involve the deceased patient's relatives or members of their community. It is very important that the body is always treated with respect and according to religious prescription.

Regarding organ donation, the Church of England asserts that:

"Giving one's self and one's possessions voluntarily for the wellbeing of others and without compulsion is a Christian duty of which organ donation is a striking example. Christians have a mandate to heal, motivated by compassion, mercy, knowledge and ability. The Christian tradition both affirms the God-given value of human bodily life, and the principle of putting the needs of others before one's own needs." [63]

There is no objection to donation of organs in Roman Catholicism but the Church does have ethical concerns about a donor being kept artificially alive for the purpose of transplantation of an organ.[64]

Organ and tissue donations, however, remain a topic of debate among Jewish and Islamic medical ethicists.

In Judaism, while saving a life is a fundamental imperative, decisions about organ donation are determined by the nature of the risk to the donor.

When there is no danger to the life of the donor – for example blood donation – there is an obligation to donate when there is a recipient who needs that donation.[65] When there is some risk to the donor – for example kidney donation – donation is permissible but not obligatory.[66] Donation is also allowed from a donor whose heart has ceased to function – for example, cornea and kidney donation.[67] 70% of current organ donations in the UK fall under these two categories.

Controversy arises when it is a question of removing organs from a donor who is brain stem dead, but who is alive if death is measured in terms of cardio-respiratory function. This is an issue, therefore, in relation to heart and lung transplants.

Let us begin with the question of establishing the moment of death in both Islam and Judaism. This is important because it has obvious implications for issues relating to the cessation of ventilation and the vacating of an Intensive Care Unit (ICU) place, as well as to organ donation.

Please see page 36 for footnote information.

The Board of Deputies of British Jews produced a practical guide for Jewish life and customs which states that:

"Organs may not be removed from a donor until death has definitely occurred, but there are varying views about what constitutes 'death'. Some traditionally-observant Jews accept the 'brain stem death' criteria, and therefore the heart and lungs can be transplanted as well as other organs. Other Orthodox authorities will only agree to removal of organs from a 'non-beating heart' donor, which reduces the range of usable organs." [68]

Nevertheless, this debate continues with some rabbinic authorities in America and Israel affirming that 'brain stem death is a halachically operational definition of death. As such, organs may be removed for transplantation under strict halachic supervision and guidance'.[69]

In Islam, two key principles inform decision-making on this subject. These are *istiṣlaḥ* and *maṣlaḥa*. *Istiṣlaḥ* is the principle of 'seeking to promote and secure common good' and 'seeking to maximise benefit and minimise harm'. *Maṣlaḥa* is the principle of 'public good' and has been frequently evoked in providing solutions to difficult issues in biomedical ethics. It, too, concerns 'considerations that promote benefit and remove harm'.

There is, however, a lack of unanimity among Muslim jurists of different schools of law on the application of these principles to particular questions in biomedical ethics. In light of this, during the 1990s and the first decade of the 21st-century, jurists belonging to all the Muslim legal schools met regularly under the auspices of the Ministers of Health of their respective countries to formulate decisions as a collective body. Some of these new rulings have been published under the auspices of *Majma' al-fiqh al-islami* (The Muslim World League based in Mecca, Saudi Arabia).[70]

At several of these meetings, Muslim jurists of different schools have ruled:

"That once invasive treatment has been intensified to save the life of a patient, life-saving equipment cannot be turned off unless the physicians are certain about the inevitability of death." [71]

However, in the instance of brain death:

"The jurists ruled that if three attending physicians attest to a totally damaged brain that results in an unresponsive coma, apnoea, and absent cephalic reflexes, and if the patient can be kept alive only by a respirator, then the person is biologically dead, although legal death can be attested only when the breathing stops completely after the turning off of life-saving equipment." [72]

In all cases, there remains the question of whether a particular action is intended to cause death, in which case it is prohibited, but otherwise, according to Abdulaziz Sachedina:

> ***"Islamic law permits withdrawal of futile and disproportionate treatment on the basis of the consent of the immediate family members who act on the professional advice of the physician in charge of the case."*** [73]

The classical Islamic legal definition of death connects death with the complete cessation of the heartbeat and, for most jurists, this factor remains the sole criterion for legal *(Shari'a)* death.

But this definition is not in itself sufficient because, according to Islamic thought, 'the formulation of a proper definition of death requires an understanding of the religious estimation of human life' along with 'an endeavour to unravel the secret of the soul *(nafs*[74]*)* or the spirit *(ruḥ)* which is infused in the body and departs at the time of death'.[75]

It is recognised within the tradition that such a separation of the soul from the body is not capable of being observed by the empirical sciences and, consequently, it is here that we find the major source of ambiguity in determining the exact moment of death within Islam.

The general acceptance of the Harvard Criteria for brain death inevitably raises some controversy within Muslim communities, but in 1986 and 1987, after intensive discussions, the Islamic Fiqh Academies in Jeddah and Mecca issued resolutions justifying the brain death criterion as Islamic. The brain death criterion has since gained public acceptance in many Muslim majority countries, albeit slowly.[76] However, as with all such issues, the notion of brain death continues to be challenged by some Muslim jurists.

All Jews would regard organ donation as a mitzvah but some fear that in doing so they may be doing harm. In the Liberal Judaism guide 'On Death and Mourning', organ donation is regarded 'as a mitzvah – a noble deed and worthy of merit. Through this act of generosity, the mitzvah of saving a human life *(pikuach nefesh)* is upheld'.[77] Indeed, 'this principle can override the Jewish objections to any unnecessary interference with the body after death, and the requirement for immediate burial'.[78] However, in 2011, Lord Jonathan Sacks, the former Chief Rabbi of the United Hebrew Congregations of Great Britain and the Commonwealth, called for the UK transplant authority to make provision within its procedures to accommodate these different categories of donation so that Jews can register for the forms of donation acceptable to them.[79] There is now a faith/beliefs option on the sign-in to the organ donation register.[80] The donor can record their agreement for medical staff to discuss their faith or beliefs when approaching their family about organ donation.

Most Muslims agree on living-related donation and non-heart beating donation, whilst there is disagreement around brain death donation. If medical staff wish to obtain consent from a patient regarding organ and tissue donation, it is important to do so within a timeframe that allows families to consult with religious figures. There might be tense debate and disagreement among family members regarding this issue.

Neither the Qur'an nor the Sunna[81] addresses the subject of organ donation as these are historic precursors to transplantation medicine. General Islamic principles or Qur'anic verses that are broad in nature are studied and examined in light of a modern context (and the specific issues that arise therein). Consequently a number of other Islamic concepts have been brought to bear on the question. These concepts can be illustrated by referring to a statement on the matter of organ donation made in 1999 by the Muslim Law *(Shari'a)* Council. This Council consisted of scholars from all the major Muslim schools of law in the UK, together with three distinguished lawyers. The statement, agreed by Sunni and Shi'a scholars, was signed by M.A. Zaki Badawi, Chair of the Council. In the light of the principles of Islamic jurisprudence, and after thorough consideration 'regarding medical opinion and several edicts issued by different religious bodies', the Council resolved that:

- **The medical profession is the proper authority to define the signs of death.**
- **Current medical knowledge considers brain stem death to be a proper definition of death.**
- **The Council accepts brain stem death as constituting the end of life for the purpose of organ transplant.**
- **The Council supports organ transplant as a means of alleviating pain or saving life on the basis of the rules of Shari'a.**[82]
- **Muslims may carry donor cards.**
- **The next of kin of a dead person, in the absence of a donor card or an expressed wish of the dead person to donate his organs, may give permission to obtain organs from the body to save other people's lives.**
- **Organ donation must be given freely without reward. Trading in organs is prohibited.**[83]

Please see page 36 for footnote information.

Following several years' work supported by NHS Blood and Transplant, a fatwa was issued in 2019 by Mufti Mohammed Zubair Butt, a leading Sunni scholar, to clarify the Islamic position on organ donation stating that 'deceased organ donation is permissible in principle, providing all requirements have been met to indicate that the soul has left the body'.[84]

6.5. End of life care during the COVID-19 pandemic

On 23 March 2020, the Prime Minister announced the first UK lockdown of the COVID-19 pandemic. All aspects of life were impacted: 'non-essential' high street businesses were closed; all people (with the exception of 'key workers') were ordered to stay at home, allowed to leave only to buy food, to excercise or for medical purposes. Hospitals, care homes and hospices also faced unprecedented challenges during this time, not least of which was the impact on end of life care. As hospital admission numbers rose dramatically and COVID deaths surged, those working in end of life care found themselves massively over-worked and over-stretched in a chronically under-funded healthcare system. Healthcare workers experienced increased exposure to infection, isolation from their families, significant work pattern changes, anxiety, depression and burnout,[85] all the while dealing with inadequate provision of PPE and COVID-19 testing for staff. Furthermore, to prevent the spread of infection, hospitals, care homes and hospices introduced stringent restrictions on visitors, meaning that many families were unable to see loved ones before they died. This was additional pressure heaped upon healthcare staff who had to inform distraught family members that they could not visit loved ones. Often they were the mediators between the families and patients, facilitating final goodbyes via mobile devices or phone calls.

For those not on the frontline of the pandemic, the emotional cost was no less significant. Thousands of families had to endure the devastating experience of losing a loved one without being able to be with them as they died. As one palliative care doctor remarked:

"Restrictions at our hospital have been such that if someone is deemed to be approaching the end of life we can allow one person from their families to come and see them. and that puts a strain… because you can imagine within a family… how do you choose?"

(Doctor, London Hospital)

Moreover, the comfort and social support provided by funerals was also severely impacted with the government placing restrictions on the number of those who could attend. Given such large-scale disruptions surrounding end of life, there will undoubtedly be a psychological price to pay, with many predicting an epidemic of complex grief.[86]

The first national lockdown restrictions in the UK were relaxed at the end of June 2020. In the months that followed, the Woolf Institute decided to undertake additional research to document and explore how such extraordinary circumstances had affected the spiritual and religious dimensions of end of life care. Over the course of several months, a number of healthcare professionals, including palliative doctors and hospital chaplains, from across the UK were interviewed about their experiences of the first wave of the COVID-19 pandemic.

6.5.1. Adaptation (facilitated by technology)

The extraordinary efforts that healthcare professionals went to in accommodating the religious and spiritual needs of their patients at end of life became apparent very quickly in the course of the interviews, and just as apparent was the rate at which they had to adapt to considerable changes. Almost overnight, thousands of years of religious rituals and rites surrounding end of life were gone – rituals and rites that in normal circumstances provide both psychological and social support for patients and their families. Suddenly, hospital chaplains were donning full PPE to give the last rites to patients. Patients, who would usually be surrounded by close family, were now alone and unable to see the face of the minister reciting prayers behind layers of protective equipment.

"So on intensive care I'm in absolutely everything: gown, double gloves, you know, sort of hair net, visor mask, proper mask. It's really interesting because it does really change how you interact with somebody. It's completely different and it feels really strange. And I think the first time I did it, I was so aware of just feeling really odd… But it's amazing how you do adapt and how suddenly feels fairly normal."

(Head Chaplain, North London Hospital)

Please see page 36 for footnote information.

For one chaplain, the wearing of PPE presented issues of personhood and interrupted the ability to connect effectively with patients, particularly when addressing their spiritual needs:

"How do we project out? You know, what is my essence, my 'priestliness', my own self? How do I communicate that when it's underneath all this PPE? I was thinking about it this morning. I was trying to get a grip of this and what that means for our own personhood. And I'm thinking about that for staff as when we're in these areas where we all look the same, well, obviously we're all different heights, but it's a bit like… Cybermen in Dr Who – I see they're all the same, but underneath they're not. But it's how do they… keep a sense of themselves in that environment?"

(Anglican Chaplain, East Anglia Hospital)

Other aspects of end of life spiritual care also had to adapt very quickly. In particular the removal of the physical component of end of life rituals which involve physical connection with the dying:

"We've had to adapt ways to administer the sacraments. You know, there is an element of touch to many of them normally – the laying on of hands, that kind of thing… A fair amount of sacraments are with words, but anointing is something that's really tactile. Um, so we've had to come up with new ways to do it. We went out to Boots and bought a load of those cotton buds. So we have them already dipped in oil, so that I will use those to anoint and then throw them away. Disposable anointing sticks I call them! It's a very beautiful feeling when you're anointed. In fact, when I'm with families, nowadays, I also invite them to be anointed as well, so they can have the same connection with their loved ones, with the oil. And they feel it, and it has this incredible power. So, yeah, that's been a way of adapting."

(Head Chaplain, Hospital in South East England)

With severe restrictions on visitors to hospitals and care homes in place, technology played a huge role in not only connecting families and patients but also providing some spiritual comfort. Several interviewees mentioned that for many Muslim patients, mobile devices and phones had been used to play prayers that would ordinarily have been recited by an Iman or family members.

"That was a new challenge in providing end of life prayers. So we would sometimes be in a situation in which we would have to hold the iPad or a laptop and have, you know, one of these programmes up and running with the family members (at home)."

(Muslim Hospital Chaplain, East London Hospital)

One interviewee related that his ward had obtained several Qur'an cubes. These are cube-shaped MP3 players that play recitations and prayers from the Qur'an.[87] One doctor on a COVID ward recounted how technology provided spiritual relief not only to a dying patient but also to his family.

"So I've personally been involved in a patient's care where the family were very unhappy that he was not being transferred to ITU. He was, therefore, unfortunately, dying of Coronavirus infection on the ward. He was from a religious Muslim family. His children were quite, shall we say, demanding and vociferous in their requests, and the team on the ward acquiesced to allow one person to be essentially relieved so that he had more or less round the clock care, somebody with him. When there were gaps, such that there was no one there, we arranged for an iPad to be essentially by the bedside where they could continuously play the prayers that they wanted to say. So that he could… I mean, whether he could hear them or not doesn't matter. If he could hear them, he could hear them. And that was helpful for them albeit with some trauma before that kind of became the plan."

(Doctor on COVID ward, North London Hospital)

Much of life shifted online during the pandemic, with millions of people working from home and social contact taking place in a virtual space. To illustrate this point, Zoom's sales in the last three months of 2020 were up 370% compared to the same period of the previous year.[88] Technology also began to take a more prominent role in end of life care; in some cases, it provided families' only method of access to dying loved ones. There were some who had concerns about the impact this technological shift might have had on staff, patients and their families, and whether it could come close to replicating the high-quality inter-personal care that is the gold-standard of palliative medicine.[89] Yet, in such desperate circumstances, there was no other option. End of life care professionals, all too aware of the enormity of the situation, worked diligently, in difficult conditions, to ensure that, where possible, patients' spiritual needs were met.

6.5.2. Emotional and psychological cost of the pandemic

The true enormity of the COVID-19 pandemic is only just becoming clear, and its full impact may take decades to be realised. The International Monetary Fund estimates that it will cost the global economy $12.5 trillion through 2024.[90] Much less easy to quantify are the associated psychological costs of the pandemic. Those who suffer from mental health problems report significantly increased suffering after the pandemic and the isolation and loneliness experienced during lockdown has negatively impacted the lives of millions, particularly young people.[91]

Please see page 36 for footnote information.

The anxiety associated with the financial impact of the pandemic, social isolation, the fear of infection and the trauma of large-scale bereavement have led many to predict a mental health crisis.[92] According to the World Health Organisation, the pandemic has triggered a 25% increase in the prevalence of anxiety and depression worldwide.[93]

For those who work in the end of life care sector, the pandemic has undoubtedly left emotional scars. Healthcare staff were exposed to overwhelming stressors. For example, the agony of having to make difficult decisions; the pain of losing patients and colleagues; the fear of increased risk of infection (not only for themselves but for their families); the fear of repeat 'waves' of the disease; often they were physically separated from their loved ones for prolonged periods of time and were surrounded by overwhelming numbers of patients and a staggering death rate. The prolonged exposure to extreme physical and emotional stress has led to an epidemic of 'burnout' in healthcare staff[94] which has led to the recognition that supporting the wellbeing of healthcare workers should be a priority.[95] In their submission to the cross-party Health and Social Care Committee, the Academy of Medical Royal Colleges stated that "active national support through a sustained and coordinated approach to mental health and wellbeing" was essential for staff engagement and retention as the NHS starts to recover from the pandemic.[96]

The religious an spiritual aspects of end of life during the pandemic will also have had a major emotional cost, particularly for the bereaved. As one palliative care doctor remarked:

"What concerns many of us are that the social, psychological, emotional and, indeed, the physical consequences of Coronavirus, not for those who've had the infection but for everyone else. So, people going through a terribly difficult bereavement because they couldn't tend to their loved one and give them what they needed and indeed didn't get what they needed."

(Palliative care Doctor, North London)

The pandemic interrupted the way that people grieve. In many cases, final goodbyes were not possible, denying people the feeling of closure that can accompany bidding farewell to a dying relative. Often final goodbyes were done via video calls. Although this may be better than not having the opportunity to say goodbye, it is unclear whether it has the same cathartic effects as being there with the dying relative, in part because the physical aspect of a final goodbye is not possible; one cannot hold their loved one's hand or kiss them one last time.

Other 'normal' experiences of end of life were disrupted or made impossible, including funerals and religious rites and rituals. These are important aspects of the grieving process that allow for social bonding and collective mourning and commemoration of the deceased. These have particular importance in religious communities who have embraced death collectively and over thousands of years and have developed complex social observances surrounding the handling of the dead and dying.

When these millennia old rituals are not possible, intense feelings of anxiety and existential threat are felt throughout the community. This is because ritual can mitigate anxiety surrounding death but also partly because of another proposed function of ritual, which is to act as a type of social glue. In the absence of end of life rituals, religious communities feel heightened levels of anxiety surrounding death but also uncertainty surrounding their very existence. This is perhaps one reason why it matters to people so much, the entire identity of a community is forged and maintained by their rituals. With these gone, the community itself ceases to exist. Jonathan Boyd, Executive Director of the Institute for Jewish Policy Research, echoed this notion and described how preventing the activities and habits so important to Jewish life was 'shaking the Jewish community to its core'.[97]

Many of the interviewees were concerned that the disruption to the grieving process caused by the pandemic would lead to a wave of issues surrounding complex and delayed grief:

"I think we need to prepare ourselves for another epidemic, one of complicated grief or the presentation of emotional disorders that have arisen from the loss suffered during the pandemic. For us as chaplains, we must prepare ourselves for a wave of people who are desperately seeking answers to the pain and hurt they feel at having lost loved ones and not being able to have adequately grieved for them."

(Hospital Chaplain, London Hospital)

Please see page 36 for footnote information.

7

Case Studies

7.0 Case Studies

The handbook has explored various themes within diversity in end of life care. How can we make practical use of this knowledge? There are, indeed, many ways of engaging with the content. Case studies form a crucial part of learning and can be used for group training. They can offer a great deal of insight into a particular topic or situation. They require participants to think through a situation and consider how to apply what they have learnt to solve or mitigate the matter in hand.

In this section, the first edition presented readers with 12 case studies – four from each faith tradition. End of life care is not the preserve of the elderly. Whilst the first nine focus on adult patients, the latter three centre on child and teenage patients.[98] This edition incorporates two further cases related to the COVID-19 pandemic.

Each case study is a real-life scenario experienced by healthcare professionals, recorded for Woolf Institute research purposes and presented here verbatim.

Here are some recommendations to follow for group training:

- **Each group should consist of no more than 10 participants to enable all attendees to voice their opinions;**
- **Each group should include a blend of healthcare professionals and volunteers to hear different experiences;**
- **Each session should last around 1.5 hours with the opportunity to discuss two case studies, topics dependent on the requirements of the group;**
- **The facilitator should introduce the purpose of the group discussion and have some knowledge and/or experience of the specific topics;**
- **Once the case study has been read aloud, 5-10 minutes should be allotted for personal deliberations before opening the discussion to the whole group.**

Consider each case study with reference to some or all of the following general questions, which have been used as a starting point at the Woolf Institute Diversity in End of Life Care training programmes:

- **Have you encountered a similar situation?**
- **How could the stress and/or panic that arose in this situation have been mitigated?**
- **How could links to different religious organisations in the community help hospice or hospital staff in such a scenario?**
- **What would you advise your hospice or hospital to do in the future and what impact do you think this will have on patients and their families?**

Cases, such as those that follow, are often complex and involve intricate decisions. It is important to remember that there are no hard and fast rules or simple answers to questions about the impact of religious beliefs and practices on end of life care, as there is tremendous diversity and difference of opinion within every faith community. Each situation must, of necessity, be individually considered and it is not possible to offer any single approach to end of life care. As mentioned, the above questions will prompt discussion.

After each case study, additional contextualised notes have been provided. These too should be utilised during the group discussions.

Healthcare professionals will identify with many of the features in these cases and may have experienced similar situations from other faith traditions which they should draw on during the group discussions.

Please see page 36 for footnote information.

7.1. Case Study 1: Advance care planning

Case reporter: Hospice staff member
Patient's faith background: Christian

One of our patients was a young Christian woman in her 30s. She had breast cancer so badly that it had deformed her. She had not sought any treatment because she believed that, if she prayed hard enough, God would perform a miracle and save her. She had a 7 year-old daughter for whom she had made no plans because she believed that God was going to save her. She maintained this stance until the end. She believed that if she prayed and was with God every second of the day, she would be saved.

Whenever anyone mentioned making plans for the child, she would ignore them and tell them to go away. Whenever speaking about her experiences of life, she would only speak about the friend of a friend who had been cured, or the gift that God had bestowed on another family that she knew. She felt that because she had been good all her life and she had been forgiven her sins, that it was her turn to be saved and, therefore, she thought that all the staff were wrong.

Additional note for Case Study 1: Without effective communication, religious and cultural sensitivities remain as obstacles to positive engagement with healthcare staff. Understanding this patient's view on suffering and how God will intervene may alleviate the distress to both the patient and members of staff.

7.2. Case Study 2: Advance care planning

Case reporter: Hospice staff member
Patient's faith background: Muslim

Advance care planning is very difficult when patients or their families are in denial about the fact that the patient is dying. We once had a young Muslim patient from Somalia who was dying and she deteriorated very quickly. She had young children and a husband, but her family were all in denial about the fact that she was dying, so when she died, they were not at all prepared for it.

The family's reaction to the death was very hysterical. Staff understood that this reaction could be normal cultural practice. However, this, and having to prepare for a funeral within 24 hours when there had been no planning beforehand, caused anxiety levels to rise among staff and family.

The family also had no affiliation with a mosque to which they might have turned, so there was a lot of pressure on staff as well as on the family. Staff called a local imam who helped them to organise the funeral, but the situation was much more awful for all concerned than it would have been if planning had been allowed to happen in advance of the patient's death.

Additional note for Case Study 2: Family denial is, of course, common across families of all backgrounds especially when death occurs at a prime age. It is good practice for hospitals/hospices and mosques (and, indeed, other places of worship and religious communities) to build an ongoing relationship, so as to be aware of each other's needs in advance, and so mitigate the distress caused by such situations.

7.3. Case Study 3: Withholding, or withdrawal of, treatment

Case reporter: Hospice staff member
Patient's faith background: Christian

In the hospice, I was treating a Christian woman in her late thirties. She felt that she had done bad things in her past and that she was being punished for her evil deeds by getting cancer.

She was very clear with us that she had to experience the pain as punishment and refused pain-killers of any sort. Experiencing the pain was her way of repenting for the acts that she had done. When she began to explain what she had done, we did not think that there was anything that a lot of people with human needs had not done themselves, but, for her, they were not forgivable without repentance.

As a team, we watched her suffer and, at times, tried to find ways to help her work through her spiritual pain, but she would not budge and we had to respect this. This situation was very difficult for the team, especially as we thought that she really had not done anything to deserve the suffering she experienced. Yet, she believed that she had and it was her decision to make. We did respect her wishes, even when she was unconscious.

Refer to Additional note for Case Study 1.

7.4. Case Study 4: Patient-caregiver relationship and communication; chaplaincy support

Case reporter: Hospital doctor
Patient's faith background: Jewish

A 75-year-old Orthodox Jewish man was brought in to Accident and Emergency after a cardiac arrest. He was in a very serious, probably irreversible condition, and there was no evidence that his brain had survived the attack. He was the head of a large family and there were several relatives waiting to hear news of his treatment. Initially, I felt that they didn't have a great deal of trust in the hospital to look after the best interests of their loved one. I was also concerned that they did not fully understand the seriousness of the situation; they were absolutely adamant that we do everything possible.

The following morning, things began to look even worse. There was no sign of brain activity and he was still on a balloon pump and inotropes. His kidneys had stopped working and he hadn't passed any urine. We also started to see signs of infection, which, of course, we treated. But, sadly, the other organs continued to deteriorate.

The family was understandably very distressed. I had a sense that they felt we were too quick to give up and needed to scrutinise every statement from cardiology or ITU (Intensive Treatment Unit) about their father's care. They were still keen to ensure that we did absolutely everything we could, including resuscitation. After asking the advice of the Hospital's Jewish chaplain, we decided to do two things: firstly, we made sure that the ITU and the cardiologists were talking to the family at the same time which meant they were not getting conflicting messages and could ask questions of the care team as a whole; secondly, we offered to explain the situation to the family's Rabbi, both for the family's peace of mind and so that we might better understand the family's perspective.

Following this, we slowly built up better relations with the family. From our conversations and the treatment of their father, they understood that we were really trying, as they could see the efforts that people were putting in. Although the decisions made were still incredibly hard for the family, having these conversations helped to build a little more trust and mutual understanding in a very difficult situation.

Additional note for Case Study 4: Chaplains often play a key role not only in offering pastoral care to patients, families and medical staff, but also in mediating between the requirements of a particular tradition and those of the medical or care facility. Be aware that whilst your hospice or hospital may have connections to ministers of various traditions, patients and their families may prefer to consult their own minister (bearing in mind the diversity of beliefs and practices within each faith).

7.5. Case Study 5: Family intervention

Case reporter: Hospice staff member
Patient's faith background: Muslim

I once visited a lady in the community who was very symptomatic; staff advised her to come to the hospice in order to better control her symptoms. When I arrived to assess her, the house was full of members of her extended family and I was not given the chance to speak with the patient who additionally did not speak English very well. This made the situation more difficult. The family refused an interpreter because they were afraid that an interpreter from the community might know them and they did not want anyone from outside interfering with such a sensitive matter in their family.

The family said that it was important in their culture to look after their family members in their own home when they were unwell. I tried to explain that staff would take the patient to the hospice, treat the symptoms and then send the patient home again, but the family could not understand that she would come home from a hospice. It was difficult because there was a lot of noise and people were speaking over each other. Family members had different opinions about what should happen and I think there was a sense of fear that if the lady came into the hospice, she might be at the end of her life and die. When I got a chance to speak to the patient herself, she said that she was finding it overwhelming but thought that it would be good if her pain and symptoms could be treated somewhere.

When I returned to the hospice, I received a phone call from a family member who had not been present at the house. He was a doctor and apologised for the difficult experience that he knew I must have faced visiting the patient's house. He informed me that a decision had been made that the patient would come into the hospice in order that her symptoms could be treated. The patient came into the hospice, her symptoms were treated and she returned home. The family were then all very happy and apologised for their behaviour.

Additional Note for Case Study 5: Many Muslim patients from non-British backgrounds have English as a second language. Language, and the use of interpreters, whether professional or from within the family, increase the complexity of situations, in which issues of religious belief and practice need to be taken into account. Refer to Section 6.3.1.

7.6. Case Study 6: Family intervention

Case reporter: Hospice staff member
Patient's faith background: Christian

There was a couple recently; they were Christian and had a great belief in God. The husband was the patient. He was clearly dying. But his wife would just not accept this and did not want to have any conversations about death. Every time the doctor brought the conversation towards death, she would become really emotional and just walk out of the room. Obviously, there were questions about resuscitation, whether we should be feeding the patient, about their preferred place for care. But in the end, none of these things were discussed… when it came to resuscitation, she was saying that he should still be resuscitated. But the medical team made the decision that this would not be in his best interest.

On the day he died she was still feeding him, sitting him upright, putting food in his mouth. I was trying to tell her that he did not really need food, that we should just leave him be and keep him comfortable. But she just kept saying 'No, no, no; he's eaten all his breakfast and he'll eat all this'. But he was unable to do so.

He died that night and, as expected, she was hysterical and very upset. She was at the nurses to bring him back. She was insistent. The brother-in-law was just as bad. He wanted the chief executive to come on the ward, so that they could bring him back. We then tried to get the family into the quiet room because, obviously, this was in amongst the other patients. But the only way the wife would go into the quiet room was if they brought her dead husband with her. So, however much we explained at the end, she just could not accept it. She had all her church friends there. But they were all the same. Not one of them could accept that he was dying.

Additional note for Case Study 6: It is always important to deepen the care staff-patient-family relationship. Asking patients – and sometimes relatives – about their faith and beliefs can provide an insight and better understanding for staff to build trust and awareness.

7.7. Case Study 7: Patient-caregiver relationship and communication; culturally specific gender relations

Case reporter: Hospice staff member
Patient's faith background: Jewish

What was different with this family was the touchy-feely bit. Sometimes you cannot help yourself from touching relatives or patients, to comfort them, but in this case, you could not touch the dad [a relative]: you were not allowed to do that. When it happened he just stepped back and said: 'You're not really supposed to touch me'. One of the female staff members said: 'I'm really sorry I didn't mean to offend you'. She was a bit embarrassed and thought she should have known that.

It does constrain what your normal practice would be in those circumstances. Being caring is often touching; it's consoling. It is thinking more about what you have to do next, rather than just having your natural responses in these situations; that's hard.

Additional note for Case Study 7: 'Pulse Today' notes that 'Physical contact between members of the opposite sex is forbidden so many Orthodox Jews will not shake hands with members of the opposite sex. Orthodox patients may feel more comfortable with health care workers of the same sex. Most Orthodox Jewish women will not mind seeing a male doctor, although if given the option they may prefer a female doctor, particularly when an intimate examination is required. Many Orthodox Jewish men would not be happy to see a female doctor'.[99]

Please see page 36 for footnote information.

7.8. Case Study 8: Patient-caregiver relationship and communication; culturally specific gender relations

Case reporter: Hospital doctor
Patient's faith background: Muslim

There was a fairly devout Islamic couple from the Middle East. The wife, who was in her early thirties, was the patient and I felt I needed to engage on quite a personal level with her on issues about her reproductive history, whether or not she might be pregnant, and the implications of kidney disease. I felt that, for cultural reasons, the male partner was overly dominating during the discussion – and whether this is a cultural or religious issue, I'm not sure. I felt that the patient was inhibited about what she could tell me with her husband there and there was resistance to him leaving.

Additional note for Case Study 8: There are many examples of situations where it can be difficult to disentangle religious from cultural issues; at times, there can be significant overlap between the two. A one-to-one conversation may be possible but the approach needs to be made sensitively. It might be helpful to seek the advice of a Muslim chaplain or of another female family member to understand better both the limitations and the possibilities of this particular cultural and religious situation, in order to see if there is a way to overcome the impasse and respond to this patient's needs appropriately.

It is also important to remember that personal issues rather than cultural or religious issues may be the key factor (though, again, these can be difficult to disentangle). Attention should be paid to whether there are warning signs of controlling or abusive behavior which create ethical or legal responsibilities related to domestic abuse. It is important not to suspect any particular religious or ethnic group is more prone to domestic abuse, and it is also important not to ignore possible signs of abuse because of religious or cultural sensitivity.

7.9 Case Study 9: Concerns after death

Case reporter: Hospice staff member
Patient's faith background: Jewish

We see a lot of Jewish patients in North London. There are sometimes issues around getting death certificates quickly, both in the hospital and in the community, especially if it's a Friday or Saturday. There are some GPs who are very good and leave their mobile numbers and will come and certify a Jewish patient at the weekend, so that they can get the burial done quickly. But that is not common.

One of my colleagues had trouble one weekend when a patient had recently been discharged from hospital and so had not been seen by his GP all that recently. There was a lot of difficulty in getting a certificate. He went home from hospital and died very quickly. and my colleague spent hours trying to get a doctor who had actually seen him before he died, either from the hospital, or one of the community doctors.

It is certainly something that we think about whenever we have a Jewish patient – making sure that a doctor has seen them recently – what will happen if they die over the weekend and they need a certificate? Sometimes we need to get a GP to see a patient on a Friday evening so that it can be sorted out.

Additional note for Case Study 9: On-call rotas and out-of-hours GP services do not always help. Joined up thinking between GPs, hospitals and local authorities are essential and healthcare professionals need to 'know the ropes' for both Jewish and Muslim patients. When confronted with a situation in which a patient's religious beliefs and practices have an impact in the healthcare setting, it is important to speak to the chaplain. Refer to Additional Note for Case Study 4.

7.10 Case Study 10: Informing children of their diagnosis; Advance care planning

Case reporter: Children's Hospice staff member
Patient's faith background: Christian

The situation I am thinking of concerns a young boy, approximately 14 years old, who was able to move around, talk, was passionate about football and loved playing for his local youth team. He had a lump on his leg, which was investigated and found to be a tumour. The prognosis was very poor and he was likely to die within the next few weeks. His parents decided that they did not want to discuss the situation with him, but agreed to come to the hospice to use the hydro pool as that, they told their son, might help to get the strength back into his leg.

He and his family came to stay at the hospice. He constantly asked when he was going to be able to get into the hydro pool and was getting very cross that staff were not able to give him a clear answer. He became very angry, shouting at staff because 'you are meant to be giving me rehab'. Staff tried to talk to the family about the situation, but the family refused to discuss his prognosis with him. It was clear that the tumour had now advanced to a point where it was not appropriate for him to use the hydrotherapy pool. His parents were also reluctant for him to have too much pain relief, as they did not want him to be reliant on painkillers as this would not be good for him. Sadly, he died in great pain within

a few days of coming to the hospice. When he died, his mother became hysterical, throwing herself onto the floor, beating herself, wailing loudly. This shook the staff, as it was an extreme reaction. The family wanted to have the funeral in Ireland, where they were originally from, and wanted this done within 24 hours as was the custom in Ireland. This was difficult to achieve due to the lack of advance care planning. In the end, for several reasons, the family had to accept a burial at the local cemetery.

The fact of not being able to be open with this young person, the denial of the prognosis and not being able to give as much pain relief as staff felt was appropriate; along with a very hysterical reaction immediately post death by the mother did shake the staff. It was also difficult to deal with the knowledge that the funeral that the family would have liked to have had could not be put in place. A debrief session was held for all staff, which enabled their concerns to be voiced and heard.

Additional note for Case Study 10: In many cases, it is difficult to disentangle the religious from the cultural issues at play. As discussed in Section 4, in both Judaism and Islam, an expedient burial (within 24 hours) is undertaken. However, this case provides a cultural need for a quick burial as it was the 'custom back home'.

7.11 Case Study 11: Family intervention; the Jewish Sabbath

Case reporter: Hospital nurse
Patient's faith background: Jewish

In paediatric anaesthetics, I was taking a child up to theatre and met the child's father: he said that he could not sign the consent form. The father explained that he was an Orthodox Jew and that, in his faith, it is not possible to write on Shabbat [the Jewish Sabbath], although, later, I learned that in cases that are life and death, this rule can be broken.

At first, this was extremely perplexing: almost to get through the gates of theatre, you need to have the consent form signed. But, in the end, it was managed by documenting that the father had not signed the consent form but had given verbal consent. The doctor wrote down that we had instructions and, in this case, it was absolutely fine, the operation went ahead. But it does take somebody on the team to take personal responsibility in order to do this. Later, I wondered how this issue would be dealt with in a hospital with less experience of Jewish patients or in a situation where time was more pressing.

Additional note for Case Study 11: For Orthodox Jewish patients, in particular, there are sometimes issues about what can and cannot be done during the Sabbath. Firstly note that writing on the Sabbath is not permitted except in a critical situation. Secondly, a member of staff can assist but must not be told directly what to write. In this case study, e.g., the father could explain to the member of staff that he would really like the child to have the operation and is agreeable. They could take notes of what the father said and hand these notes to the doctor. Another example relates to contacting families in an acute situation.
Some family members will pick up the phone even when they are unable to do so normally. Others will find it more difficult and will give contact details for someone who can walk to their home and notify them about what's going on. In another example, the patient will not use the call-bell on the Sabbath if the patient's request is not a matter of life and death.

7.12. Case Study 12: Dignity of the dead

Case reporter: Hospital doctor
Patient's faith background: Muslim

We had a 4 year old; she was just over the toddling age… a Muslim child involved in a road traffic accident in which she was struck by a car. She succumbed to those injuries by the time she got to Accident and Emergency. These are difficult circumstances – this is an infant death which is about as tragic as it gets really, for family, carers and the hospital medical staff. And you also have a family with a certain cultural belief which directs them against certain standards that we have in the Western world such as, for example, open autopsy.

One has to take into consideration their faith and their cultural beliefs, and so in that situation, I think the coroner quite rightly decided that it might be reasonable to do post-mortem imaging to (a) see if there was anything suspicious which might be identifiable by this process and (b) give an overall idea of the extent of the injuries and whether the extent of the injuries were acceptable in terms of the child succumbing in the interval between the accident and the child reaching the hospital. The child was brought to our department and underwent an MRI scan and a CT scan. From my point of view, I knew that trauma was the index here and trauma is best assessed by CT as well as MRI.

Additional note for Case Study 12: A Muslim child is washed, prayed over and buried in the manner similar to that of an adult. Also refer to Section 6.4.2.

7.13. Case Study 13: Recognising spiritual needs in advance

Case reporter: Hospital Chaplain
Patient's faith background: Christian

In those early days of COVID, everything was so intense. Staff were so over-worked, exhausted. The whole country was dealing with this disease that was killing people and people were scared, of course they were. On the COVID ward in the hospital where I work, it was so stretched – in terms of resources – that sometimes staff felt like they were doing all they could just to keep things functioning and going. So it was inevitable that issues such as spiritual care needs, might have been secondary considerations.

There was one elderly guy on the ward, who had COVID and was deteriorating. He had spent 30 years of his life as a warden at St Paul's Cathedral, so religion was clearly important to him, particularly the Anglican Church. I learned from one of the ward sisters that he had died in the night and I said to her "why did no one call me?" – As an Anglican chaplain, I know what comfort he would have had from me coming to see him. Even now, months later, I still think about it and it makes me so sad that I couldn't give him what I know would have been a great comfort to him before he died.

Things did actually change as things went on and got worse. I think the scale of the dying made people, the staff and patients, recognise the need for a religious 'presence', if you will. There were occasions when I would actually get calls to visit patients from the doctors – that had never happened before the pandemic. It was normally just from the ward sister or nurses. So I think that maybe the pandemic made people in the hospital recognise that role that we could play a bit more, and, certainly, it made us a bit more visible than before or that we're all on the same team. I remember popping in to a ward one morning and asking "So how's the ward doing?" and I got so much more information than I would usually get. and I wondered – as I obviously don't usually wear scrubs – if it's because I'm dressed like them?

Additional note for Case Study 13: The role of communication around sensitive issues like religious sensibilities is such an important aspect of positive engagement with healthcare staff. Even if a patient does not explicitly ask to see a chaplain, it might be preferable to have the chaplain involved with that patient earlier on in their care.

7.14. Case Study 14: Recognising how a spiritual crisis can impact patients' care

Case reporter: Hospice nurse
Patient's faith background: Christian

A patient experiencing a spiritual or religious crisis can have a major impact not only on the patient but also the staff – it's very upsetting to watch someone going through such an experience. I remember an elderly, male patient who had been sent to the hospice with his wife. Both of them had terminal cancer. The wife had passed away a few weeks prior and this severely affected the patient.

He had been a devout Catholic all of his life; it was an extremely important aspect of who he was. However, since both he and his wife had been diagnosed with cancer, he began to question his faith. By the time they arrived in our care, he was already angry at God for allowing such unfairness and had renounced his faith. However, things deteriorated after the wife died. He started refusing to eat or communicate with staff. I would walk past his room and hear him moaning like a wounded animal. It was awful to hear someone in such distress and knowing that no amount of medication could help alleviate that pain. It was spiritual pain; we couldn't treat that.

I asked him if he would like to see a priest but he was non-responsive. Having been brought up a Catholic myself, I thought that perhaps seeing a priest might have helped to alleviate his suffering, but at the same time it was his relationship with God that seemed to be at the heart of his pain so perhaps the presence of a priest would make him worse.

He died later that day, angry at God. I still think about him sometimes and wonder if had a priest been called, it might have alleviated some of his spiritual pain but it's impossible to know; it might have made him worse. But for all the staff, it was awful to see someone in such existential agony and know that we could not help ease the cause of that distress. It also showed me just how much a spiritual crisis can affect physical health, and how a clinical paradigm could not – in this case – adequately address that, simply treat physical symptoms.

Additional note for Case Study 14: Many practitioners report that patients, who have not been religious during their life, will often either revert to the faith of their upbringing or ask to see the relevant religious person. However, when a patient renounces their faith at end of life, it provides a complicated scenario for healthcare staff. The question of what is appropriate or what is not is almost impossible to answer. However, in such a scenario, it might be best practice to be led by the wishes of the patient.

1 Preface

[1]For further information on the Woolf Institute training, refer to Section 10.1 and https://www.woolf.cam.ac.uk/training/healthcare.

2 About this Handbook

[2]https://www.ons.gov.uk/aboutus/transparencyandgovernance/freedomofinformationfoi/muslimpopulationintheuk/.

3 End of Life Care in the UK

[3]The Roman Catholic religious orders often had/have branches or houses in the UK as well as in France, Belgium or Ireland. Examples: Mary Aikenhead, of the Irish Sisters of Charity, established St Vincent's Hospital in Dublin in 1834, which became Our Lady's Hospice for the Dying in 1879. (Refer to 'Hospice in Historical Perspective', *Encyclopedia of Death and Dying*, accessed 23 May 2019, http://www.deathreference.com/Ho-Ka/Hospice-in-Historical-Perspective.html.); St Joseph's Hospice in Hackney began as a foundation by the Irish Sisters of Charity, now called Religious Sisters of Charity, which came to London in 1900 and the hospice opened in 1905. (Refer to 'Our History', St Joseph's Hospice website, accessed 23 May 2019, https://www.stjh.org.uk/about-us/our-history.)

[4]Michael Wright and David Clark, 'Cicely Saunders and the Development of Hospice Palliative Care', in *Religious Understandings of a Good Death in Hospice Palliative Care*, ed. Harold Coward and Kelli I. Stajduhar (New York: State University of New York Press, 2012), 12.

[5]It was not until the 1950s that several surveys with an eye on quality of (end of) life were conducted on elderly care and charitable home facilities in the UK. The results revealed very poor conditions, neglect and widespread suffering among dying patients, and were, therefore, pivotal in the move towards the establishment of the first hospice care facilities. Saunders, 'The Evolution of Palliative Care', 430.

[6]Cicely Saunders, 'The Symptomatic Treatment of Incurable Malignant Disease', *Prescriber's Journal* 4 (1964): 68-73.

[7]According to Professor David Clark, 'total pain was tied to a sense of narrative and biography, emphasising the importance of listening to the patient's story and of understanding the experience of suffering in a multifaceted way'. David Clark, 'Total Pain: The Work of Cicely Saunders and the Hospice Movement', *American Pain Society Bulletin* 10 no. 4 (2000): 13. Emphasising the particularity of the individual resonates with certain religious conceptions of the individual too – writing from a Christian perspective, Janet Soskice notes, 'with their emphasis on God as Creator of all, [Christians] understand their god to be a God who cares about everything in particular' (Janet Soskice, 'Dying Well in Christianity', in *Religious Understandings of a Good Death in Hospice Palliative Care*, ed. Harold Coward and Kelli I. Stajduhar (New York: State University of New York Press, 2012), 127). End of life care is, therefore, shaped by the individual personality, tastes and wishes of the patient. Saunders' notion of 'total pain' reinforces the idea that human beings are more than simply material – although the secular domain of palliative care may not employ the specifically religious language of the soul, the emphasis on the whole person aligns with the Abrahamic idea that we are more than just our bodies: there is a spiritual dimension to the human being to which we must also attend.

[8]David Clark, 'Can Palliative Care Improve Society? Cicely Saunders and the Moral Order of Dying', *University of Glasgow End of Life Studies Blog*, 3 March 2018, http://endoflifestudies.academicblogs.co.uk/can-palliative-care-improve-society-cicely-saunders-and-the-moral-order-of-dying/.

[9]Refer to this list in Adrian Aldcroft, 'Measuring the Four Principles of Beauchamp and Childress', *Biomed Central Blog*, 13 July 2012, http://blogs.biomedcentral.com/bmcseriesblog/2012/07/13/measuring-the-four-principles-of-beauchamp-and-childress/.

[10]Shahaduz Zaman et al., 'A Moment for Compassion: Emerging Rhetorics in End of Life Care', *Medical Humanities* 44 no. 2 (2018): 140-143.

[11]For a study of conflicts between the four medical principles in action scenarios among medical students in Australia, refer to Katie Page, 'The Four Principles: Can They Be Measured and Do They Predict Ethical Decision Making?', *BMC Medical Ethics* 13 no. 10 (2012).

[12]Cicely Saunders, 'Evolution of Palliative Care', 432.

[13]For further information about these ethical principles, refer to https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life.

4 Demographics of End of Life Care in the UK

[14]Refer to 'Religion', Office for National Statistics, accessed 12 December 2018, https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/religion.

[15]The UK Population is Ageing', Office for National Statistics, August 2019, https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/august2019#the-uks-population-is-ageing.

[16]The UK Population is Ageing'.

[17]Statistician's Comment', Office for National Statistics, August 2019, https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/august2019#statisticians-comment.

[18]https://www.ons.gov.uk/aboutus/transparencyandgovernance/freedomofinformationfoi/muslimpopulationintheuk/.

[19]Sarah Abramson et al, 'Key Trends in the British Jewish Community' (Institute for Jewish Policy Research, 2011): 7.

[20]Refer to 'Religion by Age and Sex', Office for National Statistics, release date 16 May 2013, https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/religion/articles/fullstorywhatdoesthecensustellusaboutreligionin2011/2013-05-16#religion-by-age-and-sex.

[21]Ibid.

[22]Refer to http://www.brin.ac.uk/ and https://faithsurvey.co.uk/uk-christianity.html.

[23]Refer to 'British Muslims in Number: Briefing 3: Doubling in Number of Elderly Muslims', August 2015, https://mcb.org.uk/wp-content/uploads/2015/08/BMINBriefing3_Aug2015.pdf.

[24]Refer to Table 1, 'Local Authorities with the Highest Proportions of Main Minority Religious Groups, 2011', Office for National Statistics, release date 11 December 2012, https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/religion/articles/religioninenglandandwales2011/2012-12-11#measuring-religion.

5 Understanding Diverse Faith Perspectives

[25]'Afterlife' is not a term specifically used in the Christian faith but rather from a more generalised vocabulary. The term is used regularly in Muslim discourse and most Muslims would recognise what it means. In Judaism, it is suggested that, in the afterlife, the soul is liberated from the body, returning closer to God.

[26]In the Abrahamic traditions, the various practices and rituals at the end of life (like the declaration of faith in Judaism and Islam) are intended to enable a spiritual reconciliation with God and a turning 'inward' as individuals prepare to leave the earthly body.

[27]For further information, refer to https://www.bod.org.uk/.

[28]Akiva Tatz, *Dangerous Disease and Dangerous Therapy in Jewish Medical Ethics: Principles and Practice* (Southfield, MI, 2010), 31 and 101.

[29]Elliot N. Dorff, 'The Jewish Tradition: Religious Beliefs and Healthcare Decisions', part of the *Religious Traditions and Healthcare Decisions Handbook Series* published by The Park Ridge Center for the Study of Health, Faith and Ethics (N.D.), 3.

[30]Jeanne Samson Katz, 'Jewish Perspectives on Death, Dying and Bereavement' in Donna Dickenson, Malcolm Johnson and Jeanne Samson Katz, eds., *Death, Dying and Bereavement*, 2nd ed. (London: The Open University and SAGE Publishers, 2000).

[31]The Jewish calendar follows the lunar cycle which means that the English dates for these festivals will vary from year to year. Details of Sabbath, festival and fast dates and times can be found at https://www.kosher.org.uk/category/shabbat-times-festival-fast-dates.

[32]Religious prescriptions around cremation vary from tradition to tradition, with Orthodox Jews maintaining a strict prohibition on cremation, while Liberal and Reform Jews allow it. Also refer to 5.5. for the Muslim perspective.

[33]The Eucharist, Holy Communion, Mass and The Last Supper are all descriptions of the same rite in different denominations. Refer to Glossary 9.2. for further explanation.

[34]For further information on Christian rites at the end of life, see Sioned Evans and Andrew Davison, *Care for the Dying: A Practical & Pastoral Guide* (Norwich: Canterbury Press, 2014), 104-106.

[35]Refer to 'Ethnic Diversity' in *British Muslims*, 24-25.

[36]Refer, for example, to Vardit Rispler-Chaim, *Islamic Medical Ethics in the Twentieth Century* (Series: Social, Economic and Political Studies of the Middle East and Asia 46) (Leiden: Brill, 1993) and Abdulaziz Sachedina, *Islamic Biomedical Ethics: Principles and Application* (Oxford: Oxford University Press, 2009).

[37]Sachedina, *Islamic Biomedical Ethics*, 168.

[38]Abdulaziz Sachedina, 'End of Life: The Islamic View', *The Lancet* 366 no. 9487 (27 August 2005): 774-779.

[39]A list of important Muslim festival dates can be found at https://www.islamicfinder.org/special-islamic-days/.

[40]The transliteration of the Shahada declaration is '*Ashhadu an la ilaha illa llah, wa ashhadu anna Muhammadan rasulu llah*'. The English translation is 'There is no God but Allah, and Muhammad is the messenger of Allah'. Also refer to Glossary 9.3. for further explanation.

[41]For further information, refer to http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/islam_and_organ_donation.pdf.

6 Aspects of End of Life Care

[42]This term is literally translated as 'elder', but refers more specifically to individuals believed to practice a certain form of spiritual healing.

[43]Full details can be found on the website for the Office of the Public Guardian: https://www.gov.uk/government/organisations/office-of-the-public-guardian.

[44]https://www.gov.uk/lasting-power-attorney-duties/health-welfare.

[45]'Care of Dying Adults in the Last Days of Life' (National Institute for Health and Care Excellence, 16 December 2015), https://www.nice.org.uk/guidance/ng31/resources/care-of-dying-adults-in-the-last-days-of-life-pdf-1837387324357.

[46]'More Care, Less Pathway: A Review of the Liverpool Care Pathway' (July 2013).

[47]*Responsa of Rav Moshe Feinstein Vol I: Care of the Critically Ill*, translated and annotated by Moshe Dovid Tendler (Ktav Publishing Inc.: New Jersey, 1996), 76.

[48]Maryam Sultan, 'Pulling the Plug: The Islamic Perspective on End of Life Care' (Yaqeen Institute for Islamic Research, 13 November 2017), https://yaqeeninstitute.org/maryam-sultan/pulling-the-plug-the-islamic-perspectives-on-end-of-life-care/.

[49]For further insights on Jewish medical ethics, refer to, e.g., Tatz, *Dangerous Disease*; for Islamic medical ethics, refer to, e.g., Sachedina, *Islamic Biomedical Ethics*.

[50]Refer to J. David Bleich, Survey of Recent Halakhic Periodical Literature: Treatment of the Terminally Ill', in *Tradition: A Journal of Orthodox Jewish Thought*, 30 (1996), 51-87.

[51]Tatz, *Dangerous Disease*, 101.

[52]Refer to Glossary 9.1.

[53]Tatz, *Dangerous Disease*, 107, notes that 'this judgement must be made by fully competent expert opinion based on the best medical information available in terms of the relevant particular disease process and its clinical stage, applied to the particular patient at hand'.

[54]Avram Israel Reisner, 'A Halakhic Ethic of Care for the Terminally Ill' (1990), https://pdfs.semanticscholar.org/a2a2/8f510384157f5b5f9e60a3544d488aadf91c.pdf.

[55]Elliot N Dorff, 'End of Life: Jewish Perspectives', *The Lancet* 366, issue 9488 (2005): 863.

[56]Bleich, 'Survey of Recent Halakhic Periodical Literature', 67.

[57]Tatz details three categories: '(a) Withholding: not starting a therapy that is not currently being administered; (b) Withdrawing: stopping a current therapy in such a manner that death is a direct consequence; and (c) Withdrawing a therapy that is being administered intermittently by withdrawing it during an interval between administrations (stopping a therapy by not starting it after a regular break in its use). This may be seen in some sense as 'intermediate' between (a) and (b).' Tatz, *Dangerous Disease*, 103-4 where he also provides examples. Additional information can be found 101-134.

[58]Ibid., 114. These basics include 'adequate fluid and attention to electrolyte balance, adequate nutrition, oxygenation and anything else that the patient would have ordinarily needed: if the patient is taking insulin, it must be continued'. For further information, refer to Ibid., 114-117.

[59]The first port of call is the hospice or hospital chaplaincy team who can advise on the appropriate contact. Alternatively, it is helpful to have contact details for local synagogues.

[60]Jonathan Romain, 'There is Nothing Sacred in Suffering – It's Time to Bring in Assisted Dying', *Prospect* (17 July 2017), https://www.prospectmagazine.co.uk/politics/there-is-nothing-sacred-in-suffering-its-time-to-give-people-the-right-to-assisted-dying.

[61]*Hadiths* refers to sayings of the Prophet Muhammad.

[62]Shlomo Minkowitz, 'Suicide in Judaism', *Chabad* website, 2019, https://www.chabad.org/library/article_cdo/aid/4372311/jewish/Suicide-in-Judaism.htm.

[63]'Leeds Diocesan Synod Motion: Blood and Organ Donation' (General Synod, February 2016), https://www.churchofengland.org/sites/default/files/2017-11/Organ%20Donation%20General%20Synod%20Briefing%20Paper.pdf

[64]Jennifer Green and Michael Green, *Dealing with Death: A Handbook of Practices, Procedures and Law*, 2nd ed. (London and Philadelphia: Jessica Kingsley Publishers, 2006).

[65]Tatz, *Dangerous Disease*, 77.

[66]Ibid., 82-3.

[67]Jonathan Sacks, 'Organ Donation in Jewish Law', *Jewish Chronicle*, 20 January 2011, https://www.thejc.com/comment/comment/organ-donation-in-jewish-law-1.20656?highlight=jonathan+sacks.

[68]'Jewish Family Life and Customs: A Practical Guide' (Board of Deputies of British Jews, 2017), https://www.bod.org.uk/wp-content/uploads/2017/11/5518-Jewish-Family-Life-Booklet.pdf.

[69]Jonah Mandel, 'Acceptance of Brain-Stem Death Reaffirmed by Rabbis' (*The Jerusalem Post*, 12 January 2011), https://www.jpost.com/Jewish-World/Jewish-News/Acceptance-of-brain-stem-death-reaffirmed-by-rabbis.

[70]Sachedina, *Islamic Biomedical Ethics*, 48.

[71]Sachedina, 'End of Life: The Islamic View', 776.

[72]Ibid.

[73]Ibid., 778.

[74]The *Qur'an* uses the term *nafs*.

[75]Sachedina, *Islamic Biomedical Ethics*, 145-146.

[76]Eich, Thomas. 'Bioethics' in Kate Fleet et al., eds., *Encyclopaedia of Islam*, 3rd edition (available online), (Leiden; Boston: Brill, 2009).

[77]https://www.liberaljudaism.org/wp-content/uploads/2016/03/death-and-mourning.pdf, 9.

[78]https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/11350/judaism_and_organ_donation.pdf, 2.

[79]Ibid.

[80]https://www.organdonation.nhs.uk/register-your-decision/register-your-details/.

[81]Refer to Glossary 9.3.

[82]Although organ donation is largely accepted amongst Muslim religious authorities, there remains a school of thought that regards the sacrality of the body as an inviolable principle – according to this view, the organs cannot be tampered with even after death. As in the Jewish context, when it comes to living donations, the risk to the donor must always be carefully assessed. In both the Jewish and Muslim traditions, those who support organ donation after brain stem death argue that the merit of saving a life supersedes the sanctity of the human body (according to the principle that necessity renders otherwise forbidden actions permissible). For more on this range of perspectives in Islam, see Shaykh Muhammad ibn Adam al-Kawthari, *Islam & Organ Donation*, https://central-mosque.com/index.php/General-Fiqh/islam-organ-donation.html.

[83]'UK's Muslim Law Council Approves Organ Transplants', *Journal of Medical Ethics* 22, no. 2 (1996):

[84]Read the full article at https://www.organdonation.nhs.uk/get-involved/news/new-fatwa-published-to-clarify-islamic-position-on-organ-donation/.

[85]https://post.parliament.uk/mental-health-impacts-of-covid-19-on-nhs-healthcare-staff/.

[86]For example, see https://www.scientificamerican.com/article/covid-has-put-the-world-at-risk-of-prolonged-grief-disorder/.

[87]https://www.lancashiretelegraph.co.uk/news/19049478.hospitals-receive-quran-cube-donations-muslim-patients/.

[88]https://www.bbc.co.uk/news/business-56247489.

[89]Katherine C. Ritchey, Alice Foy, Erin McArdel and David A. Gruenewald, 'Reinventing Palliative Care Delivery in the Era of COVID-19: How Telemedicine Can Support End of Life Care', *American Journal of Hospice and Palliative Medicine*, August 2020, https://journals.sagepub.com/doi/full/10.1177/1049909120948235.

[90]https://www.reuters.com/business/imf-sees-cost-covid-pandemic-rising-beyond-125-trillion-estimate-2022-01-20/.

[91]https://www.mind.org.uk/media/8962/the-consequences-of-coronavirus-for-mental-health-final-report.pdf.

[92]https://www.health.org.uk/news-and-comment/news/latest-data-highlights-a-growing-mental-health-crisis-in-the-uk.

[93]https://www.who.int/news/item/02-03-2022-covid-19-pandemic-triggers-25-increase-in-prevalence-of-anxiety-and-depression-worldwide.

[94]https://www.frontiersin.org/articles/10.3389/fpubh.2021.750529/full.

[95]https://publications.parliament.uk/pa/cm5802/cmselect/cmhealth/22/2207.htm.

[96]https://committees.parliament.uk/writtenevidence/10187/pdf/.

[97]Jonathan Boyd, 'The Importance of Community in the Coronavirus Epidemic', Institute for Jewish Policy Research (2020), 1, https://jpr.org.uk/documents/JB.Community.March_2020.pdf.

7 Case Studies

[98]Thanks to colleagues at EACH who suggested the inclusion of child-centred cases.

[99]http://www.pulsetoday.co.uk/treating-orthodox-jewish-patients/10862337.article.

8

Resources or Further Learning

8.0 Resources or Further Learning

This section includes a comprehensive (yet not exhaustive) bibliography of further resources (online and print). All these works are recommended but a few resources have been highlighted for particular interest.

8.1. Articles

Highlighted for particular interest

Dorff, E.N., 'End of Life: Jewish Perspectives', *The Lancet 366*, no. 9488 (3 September 2005): 862-865.

Engelhardt, H.T. and Iltis, A.S., 'End of Life: The Traditional Christian View', *The Lancet* 366, no. 9490 (17 September 2005): 1045-1049.

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'UK's Muslim Law Council Approves Organ Transplants', *Journal of Medical Ethics* 22, no. 2 (1996): 99.

Zaman, S., 'A Moment for Compassion: Emerging Rhetorics in End of Life Care', *Medical Humanities* 44, no. 2 (2018): 140-143.

8.2. Books

Highlighted for particular interest

Evans, S. and Davison, A., eds. *Care for the Dying: A Practical & Pastoral Guide.* Norwich: Canterbury Press, 2014.

Nolan, S. *Spiritual Care at the End of Life: The Chaplain as a 'Hopeful Presence'.* London and Philadelphia: Jessica Kingsley Publishers, 2012.

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Whorton, B. *Reflective Caring: Imaginative Listening to Pastoral Experiences*. London: SPCK Publishing, 2011.

8.3. Handbooks, Reports & Web Publications

Highlighted for particular interest

'An Outline of Different Cultural Beliefs at the Time of Death' (Loddon Mallee Regional Palliative Care Consortium, 2011),

http://lmrpcc.org.au/admin/wp-content/uploads/2011/07/Customs-Beliefs-Death-Dying.pdf.

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8.4. Websites

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https://www.bereavementadvice.org/

The Bereavement Trust
http://bereavement-trust.org.uk/

Child Bereavement UK
https://childbereavementuk.org/

Children of Jannah: Muslim Child Bereavement Support
https://childrenofjannah.com/

Cicely Saunders Institute
https://cicelysaundersinternational.org/cicely-saunders-institute/

Cruse Bereavement Care
https://www.cruse.org.uk/

Death Café
https://deathcafe.com/

Dying Matters
https://www.dyingmatters.org/

Hope Again
https://www.hopeagain.org.uk/

Hospice UK
https://www.hospiceuk.org/

Jewish Bereavement Counselling Service
http://jbcs.org.uk/

Jewish Care
https://www.jewishcare.org/

Macmillan Cancer Support
https://www.macmillan.org.uk/

Marie Curie
https://www.mariecurie.org.uk/

Muslim Bereavement Support Service
http://mbss.org.uk/

Sakoon
https://www.sakoon.co.uk/muslimbereavement/

Sudden
http://www.suddendeath.org/

Sue Ryder
https://www.sueryder.org/

Winston's Wish
https://www.winstonswish.org/

9.0 Glossary

This section includes a glossary of terms used in this handbook. The definitions are by no means comprehensive, but serve as an introduction to the terms.

9.1 Judaism

Bikur Cholim: Obligation to visit the sick.

Branches of Judaism (UK): Strictly Orthodox (Haredi, Hassidic), mainstream (Orthodox, Masorti), Liberal and Reform.

Chayei Sha'a: Literally meaning 'an hour's life'; often translated as 'fleeting life' and refers to patient who is terminally ill and likely to die within a year.

Goses: Patient whose situation is imminently terminal and likely to die within a few days.

Halachah: Collective body of religious laws, including Biblical law and later Talmudic and Rabbinic law, as well as customs and traditions. [Halachic (adj.): relating to, or connected with, Halachah.]

Kavod Hamet: Obligation to honour the dead.

Pikuach nefesh: Obligation to save life.

Refuah Shlaimah: Words to wish an unwell individual a speedy recovery.

Shabbat: Jewish Sabbath begins on Friday about one hour before nightfall or 15 minutes before dusk and ends on Saturday at nightfall, lasting for approximately 25 hours.

Shema: Prayer recited twice daily (morning and evening) which begins with the words, 'Hear, O Israel: The Lord Our God, The Lord is one'; traditionally the last prayer recited before death.

Viduy: Principle of making confession is the obligation of an individual to confess their sins to God.

9.2 Christianity

Branches of Christianity (UK): Anglican, Baptist, Methodist, Orthodox, Pentecostal, Presbyterian (Reformed), Roman Catholic and other smaller groups such as Quakers and Charismatics.

Eucharist: Also called Holy Communion, the Lord's Supper and the Mass by different Christian groups; one of the central services of the Christian Church, where through prayers and the reception of bread and wine, Christians believe themselves to be united with Jesus Christ in his death and resurrection.

Last rites: Final prayers and ministrations given, when possible, shortly before death.

9.3 Islam

Branches of Islam (UK): Ismaili, Shi'a and Sunni.

Fatwa: Formal interpretation or ruling on a point of Islamic law. This is given by a qualified legal scholar (mufti).

Hadith: Saying of the Prophet Muhammad.

Istiṣlaḥ: Principle of 'seeking to promote and secure the common good'.

Jum'a: Congregational Prayer recited by Muslims every Friday afternoon.

Qur'an: Central scripture in Islam.

Maṣlaḥa: Principle of 'the public good' and frequently evoked in providing solutions to difficult issues in biomedical ethics.

Nafs: Literally meaning 'self'; often translated as 'soul'.

Pir: Literally meaning 'elder'; often referred to individuals who practise a certain form of spiritual healing.

Ruḥ: Individual's spirit or soul.

Shahada: Declaration of faith recited daily. It consists of the statement: 'There is no god but Allah, and Muhammad is the messenger of Allah'. Individuals are encouraged to recite this declaration as they approach death.

Shari'a: Ethical, moral and legal code of Islam.

Sunna: Traditional portion of Muslim law which is based on Prophet Muhammad's words or acts and accepted (together with the Qur'an, as above) as authoritative by Muslims.

10

Woolf Institute

10.0 Woolf Institute

The Woolf Institute's vision is one in which discussion and engagement overcome prejudice and intolerance. It combines teaching, research and outreach, focusing on Jews, Christians and Muslims, to foster understanding between people of different beliefs and improve the way that people live together in society. We believe that real change happens and is sustained when education, training, outreach and policy initiative are based on robust factual research.

Woolf Institute education, training, outreach and policy work draws on our research projects, which examine contemporary and historic issues to better understand areas of mutual belief and areas of difference. We use our findings to explore how similarities and differences can be constructively approached to encourage peaceful collaboration between different groups and strengthen society. People from around the world and a wide variety of backgrounds interact with our research, teaching and outreach. They all share an interest in how human interactions are affected by different beliefs about God.

Website: www.woolf.cam.ac.uk
Facebook: www.facebook.com/WoolfInstitute
Instagram: www.instagram.com/woolf.institute/
Twitter: www.twitter.com/Woolf_Institute

10.1 Diversity in End of Life Care training programme

These training programmes are provided for nurses, hospital chaplains, doctors, other healthcare professionals and volunteers. The aim of the course curriculum is to empower clinical and non-clinical staff to enhance the impact of the care they provide to patients and relatives. By undertaking a study day, they can become more knowledgeable, confident and feel more comfortable offering care, empathy and compassion to patients – of all beliefs and customs – who are approaching the end of their life. This is achieved by staff better understanding some of the religious, social and cultural practices that surround death and dying.

Webpage: www.woolf.cam.ac.uk/training/healthcare
Email: diversityinendoflifecare@woolf.cam.ac.uk

10.2 Online resources

10.2.1. Publications & Blogs

Ahmed, S. and Siddiqi, N., 'Advance Care Planning and Muslim Communities' (Woolf Institute, October 2016), https://www.woolf.cam.ac.uk/research/publications/reports/advance-care-planning-and-Muslim-communities.

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10.2.2. Podcasts

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'Good Grief' (Naked Reflections, December 2020), https://www.thenakedscientists.com/podcasts/naked-reflections/good-grief

'What Makes a Good Death?' (Naked Reflections, December 2019), https://www.thenakedscientists.com/podcasts/naked-reflections/what-makes-good-death

10.2.3. End of Life Care lectures on Woolf Institute YouTube Channel

Extending Life at Any Cost? (Conference jointly organised by the Woolf Institute and the Faraday Institute for Science and Religion, 15 February 2018):

'Pastoral Reflection on Death and Dying', Reverend Dr Derek Fraser, https://www.youtube.com/watch?v=M2dZuAhC4PM

'When is Enough Enough? Dying Well in an Age of Technological Possibilities', Professor John Wyatt, https://www.youtube.com/watch?v=dlNsXt1tiXQ

'A Good Death in a Changing Religious Landscape', Naved Siddiqi, https://www.youtube.com/watch?v=lmi5EGQrhMk

'The Ethics of Withholding Treatment and Virtue Theory', Professor David Jones, https://www.youtube.com/watch?v=f4MlAZaVyBo

'The Power of a Good Death' (Woolf Institute panel event for Cambridge University's Festival of Ideas, November 2015) with Imam Yunus Dudhwala, Dr Philip Lodge, Rabbi Jonathan Romain and Sughra Ahmed, https://www.youtube.com/watch?v=Qx9SzoKdJ-o

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