

Protecting and improving the nation's health

# Faith at end of life

A resource for professionals, providers and commissioners working in communities

# About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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## **Foreword**

At the end of life, many people do not wish to be separated from the communities in which they have lived, and those close to them are likely to require local support to cope with their loss. In addition, this is a time when, for some people, spiritual matters come to the fore and can be a great comfort both to the individual concerned, their carers and their loved ones. Public health approaches to end of life care, focusing on community-centred care and support, have much to offer to maintain and promote the wellbeing of people who are dying, caring or bereaved.

Public Health England has been working with partners to promote, facilitate and evaluate public health approaches to death, dying and bereavement throughout the country. This includes work with partners to develop the Dying Well Community Charter and accompanying toolkit, as well as work to understand the public's and public health professionals' awareness, perceptions and experiences of these approaches.

This community-centred focus recognises the need for professionals, providers and commissioners to work alongside local partners to ensure that end of life care services meet the needs of local communities. Public Health England understands the importance of faith in shaping the health and care decisions of many people, and recognises that providing appropriate community care is likely to require collaboration with faith leaders and places of worship to ensure that spiritual end of life care needs are met.

Public Health England recognises that those working in community settings need to be equipped with the right skills and knowledge to do so. This resource aims to provide health and care professionals, and those responsible for commissioning and providing services, in community settings with an understanding of some of the different spiritual end of life care needs associated with Buddhism, Christianity, Hinduism, Islam, Judaism and Sikhism. This resource also provides a number of recommendations for these audiences and signposts to a number of available resources to further inform their practice. We would be delighted to hear from you in relation to this document either with suggestions for improvement or examples of how it has been used.

Professor John Newton Chief Knowledge Officer Public Health England

## Introduction

It has long been acknowledged that pain is not always only physical and can encompass psychological, social and spiritual dimensions (Saunders 1978). Accordingly, to ensure truly holistic and person-centred care at end of life, professionals and providers should ensure that any spiritual needs of the individuals they care for are addressed.

Strengthening community focused end of life care goes some way to help address a person's wishes at the end of life. Many people at the end of life do not wish to be separated from the communities in which they have lived; and for some, these communities will incorporate a spiritual element.

This resource aims to help frontline professionals and providers working in community settings and commissioners maintain a holistic approach to the people in their care. It provides information to help ensure that delivery of services and practice takes account of spiritual needs and remains appropriate to the community setting in which they work.

Spirituality can be defined in many ways and is incorporated in a vast range of belief systems, including both established faiths and individual philosophies. A person's spiritual belief may lend itself to particular practice and rituals at the end of life, particularly when associated with an established faith. Faith traditions have rituals and beliefs that influence healthcare choices, bring comfort and meaning, and can facilitate attaining peace at the time of death.

The information in this resource focuses on the practices and rituals of the largest six religions in England according to the 2011 Census: Buddhism, Christianity, Hinduism, Islam, Judaism and Sikhism. It is designed to provide those working in community settings with an understanding of faith at the end of life, to support the provision of personalised and holistic care.

Every individual's spiritual needs and wishes are different. They may be affiliated to a faith or belief system, or may ascribe to an interpretation of a faith or belief system particular to their own culture and lifestyle. As such, this resource does not negate the responsibility of professionals and providers to determine the personalised wishes of every person for whom they care.

# Community-centred approaches to end of life care

There is extensive evidence to suggest that communities that are involved in planning and decision-making about the services in their area, are well networked and supportive and where neighbours look out for each other, have a positive impact on people's health and wellbeing<sup>1</sup>.

A community focused approach should also be applied to end of life care, given that dying and death do not happen in isolation from the rest of life. Many people who are dying do not wish to be disconnected from the communities in which they live, and their families and friends require local support to cope with their loss. Currently however, many localities are not well equipped to care for and support dying people and their loved ones in their communities.

Work is being undertaken locally and nationally to engage and involve communities in end of life care to ensure that those affected by dying and death are not abandoned and socially isolated. Public health approaches to end of life care, embodied in the Dying Well Community Charter<sup>2</sup> and Toolkit<sup>3</sup> focus on the ways in which we can build local community capacity and resilience to support the needs of dying people and those around them. These approaches are being piloted locally by 'pathfinder' communities.<sup>4</sup>

This approach recognises the need for health and social care professionals to work in community settings alongside local providers and people to provide end of life care suited to the needs of the local population. In many localities, this is likely to include joint work with community faith leaders and places of worship to understand and meet any religious needs of those requiring end of life care and support in the community.

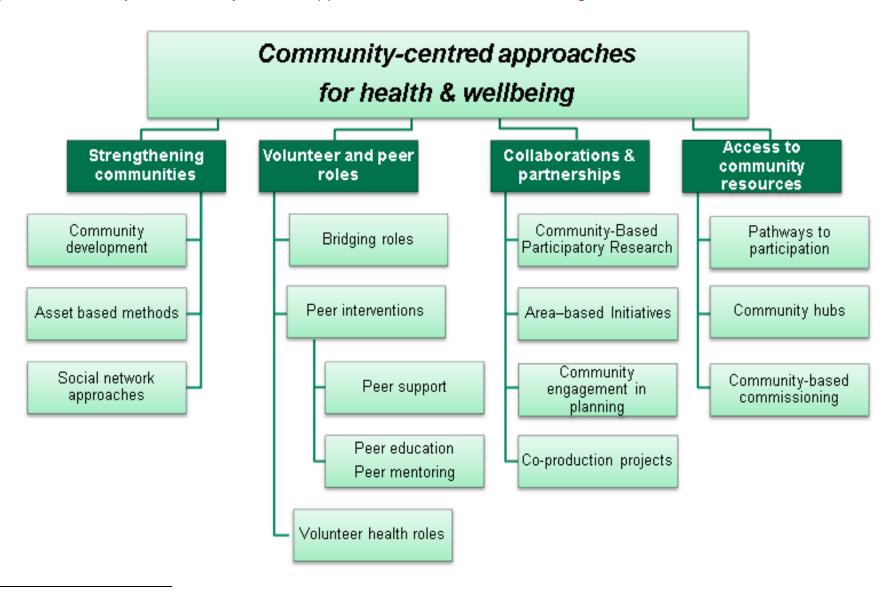
A diverse range of community interventions, models and methods can be applied to end of life care, and Figure 1 illustrates a family of community centred approaches for health and wellbeing. The case studies that follow (page 8) provide examples from pathfinder communities of how these models can be applied in practice to end of life care.

<sup>&</sup>lt;sup>1</sup> Public Health England, 2015, A guide to community centred approaches for health and wellbeing, page 4 www.gov.uk/government/uploads/system/uploads/attachment\_data/file/417515/A\_guide\_to\_community-centred\_approaches\_for\_health\_and\_wellbeing\_\_full\_report\_.pdf

<sup>&</sup>lt;sup>2</sup> National Council for Palliative Care, 2014, Dying well community charter www.ncpc.org.uk/sites/default/files/Dying\_Well\_Community\_Charter.pdf

<sup>&</sup>lt;sup>3</sup> National Council for Palliative Care, 2014, Public health approaches to end of life care: a toolkit www.ncpc.org.uk/sites/default/files/Public\_Health\_Approaches\_To\_End\_of\_Life\_Care\_Toolkit\_WEB.pdf <sup>4</sup> www.ncpc.org.uk/pathfinders-and-buddies-dying-well-community-charter

Figure 1. The family of community centred approaches for health and wellbeing<sup>5</sup>



<sup>&</sup>lt;sup>5</sup> A guide to community centred approaches for health and wellbeing, page 17

#### Case study: Cheshire Living Well, Dying Well Partnership - Cheshire

Cheshire Living Well, Dying Well (CLWDW) is the public face for The End of Life Partnership, a charitable collaborative in Cheshire aiming to transform End of Life Experience and Care.

The dedicated CLWDW Partnership strengthens the partnership processes and enables community voices to be heard. Membership of the CLWDW Partnership reflects a range of stakeholders from the public, private and third sectors.

Work has been undertaken with the Agricultural Chaplaincy Service in Cheshire, who offer a full raft of practical and emotional support to farmers and rural communities. Depression is an industrial disease in the farming community – with farming at the very top of the suicide table for occupations.

Chaplains have undertaken brief intervention training to support them in their roles and to enable their communities to engage in future life planning activity and discuss life, age, death and loss. Feedback from the initial training was positive and further follow-up work is currently being planned. http://cheshirelivingwelldyingwell.org.uk/

#### Case study: St Joseph's Hospice, Compassionate Neighbours – East London

'Compassionate Neighbours' is a volunteer-led project which aims to decrease the social isolation experienced by people who are at the end of their lives. The project matches volunteers who support people locally in three of the most economically deprived areas in East London.

The volunteers are recruited to the project via a programme of outreach to people from communities who might not traditionally access formal hospice services. This includes those whose particular culture or faith means they have specific requirements in the run up to and aftermath of death, but are not certain a hospice will be able to fulfil them.

Volunteers take part in an eight-week training programme which includes exploring their own individual responses to death, dying and loss, as well as those of others, and identifying ways to support people at the end of their lives.

Many volunteers are from cultures and faith groups who understand (and expect) strong community networks and are concerned about the social isolation of their neighbours.

The project now aims to develop a core group of the Compassionate Neighbours to become 'champions' who will help shape the project, develop a 'buddy' system and recruit other volunteers to the project. www.stjh.org.uk/neighbours

# Religious demography

#### Religious affiliation

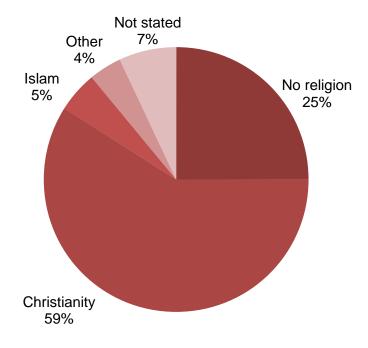
Data collected from the 2011 Census highlighted that the six biggest religions in England and Wales are Christianity, Islam, Hinduism, Sikhism, Judaism and Buddhism in order of population size.

The data also indicated a changing picture in religious affiliation over the last decade. The number of people identifying with Christianity had decreased by more than four million, though it remained the largest religious group with over 33.2 million people.

The proportion of people identifying with other religions had increased. The fastest growth in affiliation was to Islam (2.7 million people). By 2011, 817,000 people identified themselves as Hindu; 423,000 people identified as Sikh; 263,000 people as Jewish and 248,000 people as Buddhist (ONS, 2012).

The number of people with no religion had also increased, with 14.7 million people, a quarter of the population, reporting themselves as having no religion in 2011.

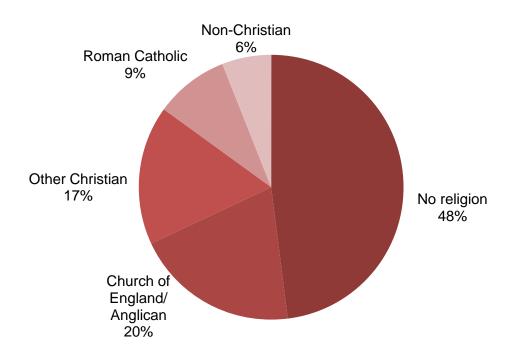
Figure 2: 'What is your religion?', England and Wales 2011<sup>6</sup>



<sup>&</sup>lt;sup>6</sup> Census 2011, Office of National Statistics - www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/rpt-religion.html

Assessing how religious people are can be difficult, and assessing it in different ways can produce different results. This is best highlighted in the disparity of findings in the Census and British Social Attitudes Survey (Survey) data. The Survey regularly reports much higher levels of respondents with 'no religion'. The most recent figures on religious affiliation from the Survey are based on 2012 data and indicate a picture very different from that of the 2011Census.

Figure 3: 'Do you regard yourself as belonging to any particular religion? If yes, which?' United Kingdom, 2012<sup>7</sup>



This discrepancy between the two data sets has been partially explained by the way in which people respond to differently worded questions, as well as the context in which they are asked. This highlights the way in which religion means different things to different people, and that conversations about faith and belief need to be sensitive to these differences.

The Survey data also found that 56% of those who indicated that they belong to or were brought up in a religion never attend religious services or meetings. This demonstrates that assumptions should never be made about the religious practices of people describing themselves as affiliated to a religion. Further, professionals should always check with individuals about the particular role they may wish their faith values to play in their care at end of life.

<sup>&</sup>lt;sup>7</sup> British Social Attitudes Survey 30, NatCen Social Research - http://www.bsa.natcen.ac.uk/latest-report/british-social-attitudes-30/personal-relationships/explaining-change.aspx

#### **Cultural diversity**

The 2011 Census data found that ethnic diversity was present in all religious groups, though the variation differed between religions. Of the 56.1 million people living in England and Wales in 2011, 19.5% were reported to be of an ethnicity other than white British. In Christianity, the proportion of white British people is higher than the general population with more than nine in ten Christians identifying as white. The religion with the largest ethnic diversity in the UK is Islam, followed by Buddhism (ONS, 2012).

The interplay between culture and religion is a complex one and is beyond the scope of this resource, however, it is important that professionals and providers are aware that cross-cultural variations are very likely to exist within each faith group. This means that members of the same faith may adopt different practices according to cultural values, and assumptions should not be made about the way in which an individual may interpret or practice their faith.

#### Equality of access to end of life care services

Though little evidence is available about access to end of life care services by different religious groups, there is some research to suggest that the access of end of life care services are considerably lower in Black and Asian minority ethnic groups when compared to the white British population. Though understanding of this inequality is far from comprehensive, some researchers have suggested that a lack of faith understanding and sensitivity by professionals can result in poor communication and reduce the likelihood of these groups to access end of life care services (Calanzani et al 2013).

# Religious profiles

The following section outlines the main end of life beliefs, practices and rituals relating to the six major faiths in England. The information outlined below does not detail the variations within each faith related to cultural background, sectarian opinion and individual levels of religious practice and interpretation.

The information below is therefore provided as a guide and should never be used to make assumptions about any individual's needs and wishes. It is important that professionals and providers explore the religious needs and wishes of each individual for whom they care. Though every effort has been made to ensure the following information on religious practices is accurate, this resource does not claim to be authoritative.

#### **Buddhism**

#### Background

Buddhism is a non-theistic belief based on the teachings of Buddha, who is believed to have lived in India between the 5<sup>th</sup> and 6<sup>th</sup> centuries BCE. Buddhism has spread widely over the centuries and there are now many variations and different schools of thought associated with it. Buddhists seek to emulate Buddha's example to achieve a transformation of consciousness known as enlightenment, up until this point Buddhists believe it is possible to be reborn.

#### Care for people who are dying and what to do after death

Buddhism places emphasis on the concept of 'mindfulness' so there is an importance to die consciously and with a clear mind. To ease the transition from life to death, and relieve a dying person's agitation and fears, family, relatives, friends and monks will repeat mantras and chant certain teachings of Buddha, known as sutras (Bauer-Wu et al 2007). Possible spiritual practices undertaken during this time may include meditation, breathing exercises, chanting and study of scripture.

Buddhists prefer to know they are dying because it allows for mental and spiritual preparation. While being cared for, some Buddhists may express culturally based concerns about treatment from health and care professionals of the opposite sex. Pain management may be a sensitive topic for Buddhists. Although controlling pain through medication may help achieve a calm state of mind, some Buddhists may refuse painkillers and sedatives so that they are fully aware, even though they may be in severe pain. Therefore, professionals must be specific when discussing the use of any

drug that may affect awareness (Barnes 1996). Such conversations should respect the autonomy of the patient and the family by sharing the decision-making process.

Depending on the level of spiritual practice at the point of death, some Buddhists may also maintain their vegetarian dietary requests, so ingesting any animal by-product, including medication, may be a problem. The plan of care for Buddhists should fully integrate spiritual suffering and concern for the person's mental state. As the person approaches death, health and care professionals should refrain from any display of emotions or behaviour that will disturb the individual's state of mind, and aim to minimise actions that may disturb the person's meditation or preparation for dying (Gyatso 1995).

Buddhism teaches that a person is not fully dead until several hours have elapsed after death has been pronounced. In some Buddhist traditions this period of time is much longer – seven or even 49 days, for example. This transient period allows the being to continue its journey to a happy state. Professionals can accommodate this spiritual practice by keeping the body as still as possible and avoiding disturbances during transport. Family members may request that the body is not touched during this period and that it is available to them to perform religious rites. All such requests should be negotiated carefully to fully support the bereaved family members.

After death, Buddhists normally cremate the body but funeral traditions may vary across the different types of Buddhists. In particular, funeral services may include a picture of the deceased and chanting and praising their qualities. It is believed by Buddhists that the mental and emotional state of the bereaved influences the state of the deceased and their rebirth, so excessive expression of grief is avoided. To help promote a good transition from this life to the next, monks continue chants for several days after the cremation (Kramer KP 1988). There are unlikely to be objections to post-mortems and organ donation, though some Far Eastern Buddhists may object.

#### Christianity

#### Background

Christianity is the main religion in Britain. There are many different Christian churches with differing structures, beliefs and rituals but the concept of one God who reveals himself as Father, Son and Holy Spirit (the Trinity) is central to most Christian teaching. Christian churches include: Church of England, Roman Catholic, Free Churches, Orthodox and other churches or groups, including Quakers, Unitarian and Independent Churches.

#### Care for people who are dying and what to do after death

People dying in their local community who practise their faith are likely to already have their own church community, which could be called on for support. It is important that health and care professionals identify this church community support at the start of their care. People who belong to a church, or those who consider themselves religious, may have particular needs in line with their particular religious beliefs.

#### Church of England (Anglican)

Prayers may be valued at the bedside. Some Anglicans may ask for the dying person to receive Holy Communion and/or be anointed. Professionals should always ask the patient or those who are important to them if they would like to see someone from their church community. Baptism or blessing for babies and young children who are dying should also be offered.

#### Roman Catholic

In addition to normal visits by someone from their church community, often with Holy Communion, the Sacrament of the Sick with anointing (commonly known as the Last Rites) can be of particular importance to Roman Catholics. This can only be administered by a priest and professionals should contact the dying person's priest or contact the local church to accommodate these wishes. Prayers after death may also be requested. The baptism of infants in danger of dying is also important.

#### Free Churches

People associated with the free churches will often welcome prayers, but many will not expect to receive Holy Communion. They may ask for prayers before and/or just after death.

Christians, regardless of their denomination, believe that the bodies of the dead should be treated with respect. Christians do not often have any objection to post mortem. Faith at end of life: a resource for professionals, providers and commissioners working in communities

Funeral services vary across the denominations and careful liaison needs to happen with the local (or family) church ministers.

Disposal of the body is by burial or cremation. The timing of the funeral will be determined by the family and services will be planned at the family's request.

#### Hinduism

#### Background

Hinduism is the third largest religion in the world with about 900 million Hindus worldwide. Unlike most other religions there is no single founder, no one scripture, no commonly agreed set of teaching or unified code of conduct. The common concepts accepted by most Hindus include the belief in the eternal self that transmigrates in the cycle of birth, death and rebirth governed by the law of karma.

#### Care for people who are dying and what to do after death

In Hinduism, death is seen as not only the end to the physical body, but a natural progression of the soul in to the next state of existence. The next step may be accepting another physical body, or a state of permanent liberation, to which many Hindu's aspire (Thakrar 2008).

In Hindu belief a dying person's state of mind at death significantly influences rebirth. Therefore the dying person and their family may take great care to create an atmosphere to remind them of their relationship with God and lead to an auspicious death. For example, a dying person may wish to have religious items around the bed to help prepare for their departure. Common items include sacred images of deities or saints, sacred flowers and garlands, rosary and prayer beads, Ganges water and religious texts (Wood 1988).

Before death it may also be important to a Hindu person that they are able to offer food and other articles of use to needy, religious persons or to the temple. Wherever possible, professionals should help to accommodate these wishes.

Some female Hindus may request a female professional to look after their personal needs. These restrictions are less likely to apply to male patients (Galanti 2008). Physical purity as well as spiritual purity is important and some may require the use of water for ablutions (Worth et al 2009). As issues regarding urinary and bowel needs are not openly discussed in public by most Hindus, constipation can be a major silent illness that needs to be sensitively approached by professionals (Skyes 1998; Lawrie 2007).

During the final stages many relatives and family members will come to comfort, offer their respects and advise on the final sojourn. All parties may take this opportunity to ask forgiveness of any inadvertent offences. To accommodate this, Hindu's may request flexibility around the standard rule of two visitors that exists in many establishments' visiting rules.

Hindu scriptures describe that hearing is the last sense to be active before death. Great care is taken to avoid saying anything that will be disturbing for the dying person, even if

they are unconscious. Emphasis is therefore placed on the recitation of the names of God. There may be soft chanting of mantras (taking the name of God), recitation of prayers or readings from sacred texts by family and visitors. These activities are to nurture a spiritual atmosphere and frame of mind. On the other hand, some patients may require time for silent prayer and meditation, especially in the early hours of the morning.

Shortly before death both the sacred tulasi leaf and Ganges water may be administered to the dying person by their family or a priest. Ideally this is done as close to death as possible (Wood 1988).

Following death, family members may gather where the body is to pay their respects, offer prayers and chant the name of God. It is important at this time that the family is consulted to see if they wish to carry out last rites, as distress can be caused if the body is touched by non-Hindus. Where the family is not available, it is important that professionals close the eyes of the deceased and straighten their limbs, ensure that jewellery and religious objects are not removed and that the body is wrapped in a plain sheet without religious emblem.

Cremations are the norm among Hindus except for children (in some traditions under the age of 27 months and in others under the age of five years) where burials may be preferred (Thakrar 2008). On the day of cremation the body is usually returned to the home of the deceased for a few hours, allowing the priest to perform the final ceremony and friends and relatives to offer their respects, however, some families may prefer to have this done at the funeral director's or crematorium. In India, cremation normally takes place by sunset on the same day as death, and while this is not possible in Britain, cremations should be carried out as soon as possible.

Thirteen days of purification and mourning usually follow a death, though there is some variation in the length of this time according to region, traditions and family background. During this time there may be a daily gathering of family members, relatives and friends. After this period of mourning another ceremony is performed to end the process. Following this the ashes are dispersed within one year of cremation. Many Hindus often travel to India to disperse them in the holy rivers, though others prefer to do so into the local rivers in Britain.

The relationship between the deceased and family does not end at death. In the Hindu calendar every year there are 15 days, known as sraddha, during which the forefathers are honoured (Wood 1988). These observations, which include acts of charity and offerings to the priests, are thought to help the departed soul in its spiritual journey.

#### Islam

#### Background

A Muslim is a person who follows the religion of Islam. Muslim's believe in God (Allah in Arabic) alone as the Creator and they follow the revelations of God's last prophet Muhammed (peace and blessings be upon him). The Quran is the holy book of Islam and is considered by Muslims to be the last revealed word of God. It is from this Holy Book and the teachings of the Prophet that Islamic practices are derived.

#### Care for people who are dying and what to do after death

Muslim death and bereavement customs are strongly shaped by religious teachings; an understanding of this narrative is important to allow care to be appropriately delivered. Indeed, there are a number of Islamic practices that Muslims nearing the end of life may wish to continue up until the point they are unable.

#### Prayers and cleanliness

Muslims are required to pray five times a day and in order to do so they are expected to perform ablutions before prayer and face the holy city of Mecca (Saudi Arabia). Remaining ritually clean is a pre-requisite for these prayers and this particularly includes being clean from urine, vomit, blood, semen and stool traces (Zafir al-Shahri 2005). Once seriously ill, and towards the end of life, patients may find this difficult, particularly if bed bound and may require help to perform ablutions. A dying person may also wish to lie facing Mecca, towards which prayers are directed (Sheikh 1998).

#### Fasting

The month of Ramadan is celebrated by fasting from dawn to sunset. Although Islamic teachings exempt the sick from fasting, some Muslims may feel obliged to uphold this important pillar of their faith (Zafir al-Shahri 2005). In such instances, health and care professionals should discuss the health implications of the decision to fast in a clear and sensitive manner.

#### Social aspects

Islamic teaching encourages Muslims to visit the sick (Al-Jibaly 1998) and as such social support for the dying person is likely to come from family and friends. Muslim visitors may wish to perform prayers while visiting and professionals should try to be as accommodating as possible to large groups of visitors and the need for prayer space.

#### **Decision-making**

In many Muslim communities decision-making is collective and involves the whole family. Muslim families of a dying person may therefore request information and involvement in the decision-making process (Zafir al-Shahri 2005). While respecting this

collective decision-making, professionals must always identify with the individual at the end of life who they wish to be involved in decision-making and work according to those wishes.

#### Wills

Islamic teachings stress the importance of writing a will (Khan 1994) while one is healthy and with capacity, and as a Muslim nears death they may be anxious about keeping this updated. If family and friends are not available, heath and care professionals should consider their suitability to being a witness to any amendments (Zafir al-Shahri 2005).

#### Charity

Many Muslims at the end of life also look to set up charitable donations and Trusts known as Sadaqa Jariyah, as it is believed that the rewards of it continue to benefit the recipient and donor long after death. In the absence of family and friends, professionals should contact a Muslim leader for advice if the individual they care for wishes to set up this form of charitable giving.

#### The declaration of faith

In the last stages of life, accompanying family and friends will often recite verses from the Quran and the Shahadah, the declaration of faith, to help the dying person reconfirm their beliefs (Sheikh 1998).

#### After death

Following death, Muslims may request that the deceased body faces Mecca, with their eyes and mouth closed and the limbs straightened. There is a religious requirement for the body to be buried as soon as possible, so those involved in processing the death certificate should be sensitive to this and do so as soon as possible (Sheikh 1998).

Islam teaches that the sanctity of the dead person is equal to that of the living, so the body of the deceased should be handled as gently as possible (Zafir al-Shahri, 2005). The body is commonly washed by family or friends. A white shroud will be used to wrap the body and prayers will be recited. Family members may feel uncomfortable for the body to be touched by professionals, so contact should be kept to a minimum (Sheikh 1998) and ideally handled by professionals of the same sex as the deceased person (Black 1987).

#### Post-mortems

The majority of Muslims normally do not wish a post-mortem to be carried out on the deceased unless required by law (ie ordered by the coroner) (Sheikh 1998).

#### Burial

Muslims are always buried and a quick burial is encouraged. Barriers to this include delay in having the death certificate issued and registering the death, the need for post-

mortem examinations and difficulties in burying the deceased at weekends and on public holidays (Sheikh and Gatrad 2007).

It is common practice for the gravesite to face towards Mecca. Usually a funeral prayer is carried out in the local mosque followed by a funeral procession to the gravesite where a final prayer will be held (Sheikh 1998). Often women are not advised to enter the graveyard. In Islam death is acknowledged as an act of God so excessive displays of mourning are discouraged among the bereaved (Al-Jibaly 1998).

#### Mourning

In Islam mourning lasts for three days, when visitors are received, and places responsibility on the religious community to support the family of the deceased in various practical ways. Professionals should not assume these social networks are always present and should be proactive in identifying the level of social support each family has available to them (Kristiansen 2012). Where available the support of an appropriate Muslim leader should be offered.

#### **Judaism**

#### Background

Judaism has been in existence for more than 3,500 years and is based on the belief in one universal God. The love of God and the wish to carry out the commandments in the Torah is embodied in the teaching of the Pentateuch (the first five books of the Bible). Jewish religion and culture are inextricably mixed and the religion has three main strands: orthodox, conservative and reformed. As such, there are many differences in beliefs and practices.

#### Care for people who are dying and what to do after death

In Judaism death is seen as a part of God's plan (Prosser et al 2012). Jews believe the body transitions from this life to the next life, known as Olam Haemet 'the world of truth'.

Orthodox Jews consider God's law binding and inflexible so as they approach the end of life patients may continue to observe the Sabbath and strict kosher dietary rules. Professionals should be aware of this and recognise that it may limit an individual's ability to undertake certain day-to-day activities, including, but not limited to, signing papers, using lifts and engaging in funeral preparations. Professionals should therefore seek to understand the implications this may have on particular individuals, and tailor planned care and support accordingly.

In Jewish tradition, a dying person should not be left alone. Many friends and family will therefore wish to sit with their relatives during the last days and hours and will often spend this time praying and reciting verses from the Psalms (Bauer-Wu et al 2007).

After death is confirmed the eyes are closed and the body should be covered with a white sheet as a sign of respect. Some families may wish to practice certain customs such as placing the body face up and positioning the feet to face the door (Bauer-Wu et al 2007). Depending on the sex of the deceased, fellow men or women will prepare the body for burial. Usually three members of the community are present. The body is washed and shrouded before being placed in a coffin for burial. Cremation is forbidden in orthodox Judaism.

Jews may wish that a Rabbi is informed when the last stages of life are approaching to enable them time to call upon the Holy Society, known as Chevra Kaddish, to perform the burial rites. Jewish tradition encourages burial as soon as possible out of respect for the deceased and ideally this should take place within 24 hours after death.

It is customary for Jewish families to arrange a 'watcher' to guard the body after death, as it is not permitted for the body to be left until the burial (Syme 1988; Lamm 1969).

Burial is usually simple; Judaism does not encourage open caskets or music at funerals (Bauer-Wu et al 2007).

The rituals of the Jewish mourning period consist of several stages, providing structure for loved ones. After the burial a candle is lit to mark a seven day mourning period, known as shiva. During this week family and friends gather together at the home of the deceased to share words of comfort and remember the deceased. A prayer service is conducted where the mourners recite the Kaddish prayer (Lipstadt 1974; Syme 1988).

Jewish teachings discourage excessive and long periods of grief. Jewish teaching provides instruction for the bereaved up to the one year anniversary of the death of their loved one. This usually consists of three days for crying and seven days for sadness, followed by 30 days of avoiding haircuts and wearing laundered clothes, and, for children of the deceased, a year of mourning observances (Lamm 1969; Syme 1988).

#### Sikhism

#### Background

Sikhism is one of the world's youngest religions and was founded more than 500 years ago by Guru Nanak who received a revelation from God. The Sikh holy book, the Sri Guru Granth Sahib i, is seen as a living guru and guide. Sikhs believe that human beings spend their time in a cycle of birth, life, and rebirth. Sikhs place importance on the need to understand and experience God, and eventually become one with God.

#### Care for people who are dying and what to do after death

When a Sikh person is nearing death it is common practice for friends and family to gather around the patient and recite verses from the Sri Guru Granth Sahib i. The Sikh religion does not put any emphasis on particular rituals that must be completed when caring for a dying person, but meditation and continual recitation of prayers are a priority. Social support is very important in Sikh tradition so professionals should be sensitive of large family networks seeking to visit the dying person.

As the time of death nears, family members may wish to increase the recital of hymns. In the situation when the family cannot perform this rite, a Granthi (Sikh priest) may be asked to step in and recite prayers. In the absence of a Granthi, family members may wish to have a recording of Sikh scriptures playing close to the dying person. It is important for professionals to be sensitive of these practices because Sikhs believe this period of recitation will help the patient fix their mind on God and leave this world detached from worldly matters (Firth 1989; Jhutti-Johal 2011). Sikhs believe if this state is not reached the soul will not be reborn.

At the time of death Sikhs may wish to repeat the word 'Waheguru', meaning the Wonderful Lord. In Sikh tradition wailing and howling is discouraged. If the patient passes away when family are not present it is important for professionals to contact the family immediately because they may wish to perform recitations and prayers. These prayers are important in accepting that death is an act of God.

Cremation is the norm for most Sikhs. It is important that it takes place as soon as possible, so professionals should aim to release the body promptly. In Sikh practices death is not marked as a moment of sadness but something that comes from God. Sikhs believe in reincarnation after death, so crying is discouraged. Family of the deceased may express their loss in different ways.

Traditionally the ashes are spread in running water and family members may request the ashes to be sent to India. After burial of the ashes, the family and friends of the deceased will gather in the temple to read more hymns and distribute a bread/pudding delicacy, known as parsad, symbolising God's blessings (Jhutti-Johal 2013). To help ease the sorrows of the family verses from the Sri Guru Granth Sahib i may be read or sung for several days. The end of the mourning period is marked by a ceremony that takes place ten days after death, known as the Bhog, to complete the readings of the Sri Guru Granth Sahib i.

## Practice recommendations

#### Health and care professionals

This section provides recommendations for those working in the community with people at the end of life, to ensure that they are sensitive to any spiritual and faith needs that the person they care for may have:

- identify if the person you care for ascribes to a particular religion, and whether they expect this to have a bearing on their end of life care
- ask whether they have particular spiritual needs related to the end of life, listen to and record these needs
- determine whether the patient wants visits from a representative of their faith and whether they have a local religious leader they would prefer
- provide care recipients and their families with access to appropriate spiritual support and links to faith leaders
- establish the appropriateness and willingness of care recipients and their families to use the words 'death' and 'dying'
- identify the role of the family in the decision-making process of the care plan
- ensure information regarding end of life care and support services are provided in the language of choice for the care recipients and their families
- seek advice and support in responding to any encounter you are unsure about with other staff, religious leaders or chaplains at the local hospital

### Service providers and commissioners

The following are recommendations for those responsible for commissioning and providing end of life care services in the community:

- ensure all staff involved in care and bereavement support are trained in faith sensitivity and effective communication
- ensure care plans include space to record faith and requirements for the individual
- undertake locality asset mapping with local communities to quantify what support is available to communities and identify where there are gaps that require resourcing
- sign up to the 'Dying Well Community Charter' with National Council of Palliative Care
- ensure that community development approaches to end of life care include collaboration with local places of worship and faith communities

## Further resources

#### Tools

NHS Chaplaincy Guidelines, 2015 – www.england.nhs.uk/wp.../2015/03/nhs-chaplaincy-guidelines-2015.pdf

Dying Well Community Charter, 2014 – www.ncpc.org.uk/sites/default/files/Dying\_Well\_Community\_Charter.pdf

Public Health Approaches to End of Life Care: A Toolkit, 2014 – www.ncpc.org.uk/sites/default/files/Public\_Health\_Approaches\_To\_End\_of\_Life\_Care\_Toolkit\_WEB.pdf

A Guide to Community Centred Approaches for Health and Wellbeing, 2015 – www.gov.uk/government/uploads/system/uploads/attachment\_data/file/417515/A\_guide\_to\_community-centred\_approaches\_for\_health\_and\_wellbeing\_\_full\_report\_.pdf

#### Sacred texts

- Buddhism There are many traditions in Buddhism and each has its own sacred text, including the Sutras, Tripitaka and the Tibetan Book of the Dead
- Christianity The Bible
- Hinduism Bhagavad Gita
- Islam The Quran
- Judaism The Torah
- Sikhism Sri Guru Granth Sahib ⇒i

For more information on the sacred texts, visit: www.bbc.co.uk/religion/religions www.soas.ac.uk/library/subjects/religions

#### Websites

BBC - www.bbc.co.uk/religion/religions

Dying Matters Coalition – www.dyingmatters.org

Marie Curie Care – www.mariecurie.org.uk

National Council for Palliative Care – www.ncpc.org.uk

SOAS library – www.soas.ac.uk/library/subjects/religions

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