

**All Wales Guidance:
Care Decisions for the Last Days of Life**

Considering Diversity Appendix

**A resource for healthcare staff to support the delivery of
person-centred care in the last few days and hours of life**

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Mae'r ddogfen hon ar gael yn y Gymraeg hefyd. / This document is also available in Welsh.

Things to consider in delivering holistic care to individuals when using the Care Decisions for the Last Days of Life Guidance

Treat me with respect.
I am a person with rights, beliefs and preferences, just like you.
I don't want to be just another name or number on your list!
It's the little things that make a real difference.

Quotes from service users & carers 2021

Each person is an individual, obvious perhaps, but there are things we need to consider in law as well as for reasons of wanting to deliver our care with the highest level of dignity and respect. This document is intended to help guide healthcare staff to be alert to and respond to individual diversity in caring for adults in their last few days or hours of life.

Please note this is a working document that will be added to and further developed over time. Feedback and suggestions are welcome to Caredecisions@wales.nhs.uk

1. General good practice points

Understanding the priorities, preferences and needs of patients who are dying and those important to them is very important, there is only one chance to get it right. To achieve this you should:

- **Speak in a language people can easily understand.** Avoid using jargon or acronyms, check the person is able to hear and understand what's been said, get a translator or interpreter involved if needed (see sections 3.10 & 4) and be aware of health illiteracy (i.e. that they may not understand the complexities of their health issue(s) or what you are telling them but may not want to embarrass themselves or you by showing this).
- Be aware of your **body language and tone of voice** – they communicate even more information than the words you use.
- **Listen carefully** to what the dying person is saying (or to their family/carer if person is unable to communicate) – there is only one chance to get this right. Plan the care *with* them and involve those important to them in these conversations where it's possible and *if* the patient wants this. The key thing is to have open, honest and regular two-way **communications**, especially as things change.
- Consider the **environment and situation** when you speak with the person and their family. Is it private, quiet, is there time for them to take everything in and ask questions? Also, to check their understanding - Does this make sense? Can I go over anything? This gives the opportunity to ask if they are uncertain and shows you are there and will give your time to help them understand. This will mean a lot to them.
- Quickly and very sensitively **establish the appropriateness and willingness** of the person and their families **to use the words 'death' and 'dying'** and again be aware of health illiteracy (see above).
- **Avoid euphemisms** – for example, say dying rather than passing away, unless the person clearly says that they don't want this (see above).

- **Consider using objects, books, easy read** forms of documents, photos or drawings to supplement information being shared.
- Consider the needs of **families and informal carers** too. Pre-bereavement and bereavement support can be invaluable so be prepared to offer information or direct patients and their families/carers to additional support.
- **Privacy** is important to all but essential for LGBTQ+ people where many, particularly those of older generation, have not told their families about their sexual orientation or partner.
- Patients may have one or more **dependants** (children or adults), pets or may have a carer whose needs may need to be considered. Not having the reassurance of arrangements in place to take care of these dependants may cause great stress and concern for the dying person.
- It's often the smallest things that can make a real difference to people's experience.
- Expect each person and their situation to be **unique**. All will have their own way of making sense of what is happening to them and their own way of dealing with it.

There are 9 protected characteristics in UK law under the Equality Act 2010, plus in Wales we have the Standards in accordance with the Welsh Language (Wales) Measure (2011). From April 2021 the Welsh Government also enacted the Socio-economic Duty contained in section 1 of the Equality Act 2010. This makes 11 elements for consideration.

These are:

- Age
- Disability
- Gender Reassignment
- Marriage or civil partnership
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation
- Welsh language (Standards)
- Socio-economic disadvantage (Duty)

2. The Law

The law (Equality Act, 2010) demands that we take every precaution possible so as not to discriminate against any person. We must also avoid any form of harassment or victimisation. A person's protected characteristics (listed above) can make them more vulnerable to discrimination whether unintentionally or otherwise. According to the Act we must all positively promote equality of opportunity and foster good relations between people who have these protected characteristics and those who don't. Treating people equally doesn't mean treating everyone the same. Instead it's about making reasonable adjustments to meet the person's own needs so that ultimately everyone receives the same standard of care. (See Appendix 1 for further information about the Act.) Delivering good care in the last days of life includes

showing respect for each individual, tailoring care to meet their specific needs, goals and preferences as well as preserving their privacy and dignity.

The following information aims to help you avoid any unintentional discrimination as part of delivering the best care possible. It presents information to help guide and support your thinking, decision making and ultimately enhance the care you give.

3. Things to be aware of...

How the dying person fits into one or more of the 11 categories listed below may impact their care needs. The only way to confirm **what matters to them and to identify their needs and preferences is to ASK THEM**. (If they are unable to communicate, those important to the dying person - their family, friends, carer, next of kin may be able to help with some of this information.)

Questions that might help you ask about things in a **sensitive way** include:

- Please help me spell/pronounce your name?
- How do you describe your ethnicity?
- Do you need any help to arrive at the ward (on second floor) or with communication? (accessibility, interpreter)
- Who do you want involved in making decisions about your care?
- Do you have any religious or spiritual needs that I/those caring for you need to be aware of?
- Would you like to have written information? What language would you prefer this in?
- How easy is it for you to organise care (e.g. do you have a computer or smart phone, someone helping you at home)?

Below, each category is considered where possible both in general terms and more specific good practice pointers. The aim is to help you tailor care to deliver the best person-centred individualised care possible in the last days or hours of life.

NB. Terms used to describe people who share characteristics can change over time. People also, of course, have the right to self-define and for this be respected, so they may not choose to use the same terms as others. The terms shown in this document are, to the best of our knowledge, understood to be current at the time of production (further information is included in Appendix 2 and 3). Your help in keeping this document updated would be appreciated: CareDecisions@wales.nhs.uk

3.1 Age

General:

- Young adults when dying may manifest regressive behaviour.
- There is an increased incidence of reduced or fluctuating capacity linked to aging e.g. caused by Dementia.

- Eyesight issues and hearing loss disproportionately affect older people. (See also 3.2 below.)
- Older patients may need more support with legal obligations.
- Don't assume all people are equally computer literate or have access to a computer/smart phone. In general, there is a higher degree of confidence in using these within younger age groups. Check that someone has access and feels confident in using IT if you are signposting them to websites or other information online.
- If at home and the carer is elderly, ask if they need more help with caring at this stage.

3.2 Disability

For suggested language associated with disability (as at May 2021), which is in keeping with the Welsh Government's adopted Social Model of Disability, see Appendix 2.

General:

- Disability can be physical, mental or sensory (hearing, sight etc). It may not be clearly visible that the person who is dying or those important to them has a disability.
- Try to quickly understand the person's communication and other needs related to their disability and respond to these. Speaking clearly is one of the most effective and common ways of communication with, for example, deafblind people who have some remaining vision and hearing. Others may require more personalised communication support such as British Sign Language/English interpreters and translators, speech to text reporters or interpreters for deafblind - see section 4.
- Learning disabled people or people with cognitive impairment may require clear, simple and possibly repeated explanations of what is happening.
- People who lip read may struggle with others wearing masks. Communication using transparent masks (where available) or via Microsoft Teams may help.
- Some disabled people may benefit from online services being offered. However not all will have access to internet or digital services for a variety of reasons. Support may be required to enable access.
- Meeting the needs of the patient's carer is equally important. So consider the needs of someone who may accompany a disabled person, or those important to the patient who may be disabled e.g. deaf and use British Sign language, blind or need wheelchair accessible facilities such as parking, lifts, toilets etc.
- Consider a person's access needs with them and arrange additional support where needed.

3.3 Gender reassignment

General:

- Ask them how they would like to be referred to. Be sensitive to the potential of needing to use different pronouns in response to gender self-identification. Using 'they/them' or the person's name instead of he/she is preferable until you are able to ask what pronouns they use. This needs to be a consideration for those important to the patient too. You may not be able to ask each person about their own preferred pronouns so be mindful of what the patient uses and follow their example.
- Maintaining a high level of privacy, such as obscuring the person well when being examined and washed, is important.
- Non-disclosure of gender identity must be upheld to ensure privacy is maintained for the transgender person. Even in death this is a legal requirement, regardless of how well known the person's transition may be to staff, carers or relatives.

3.4 Marriage and Civil Partnership (heterosexual or same sex)

General:

- When discussing those important to the patient and next of kin, try to use inclusive language such as 'partner' not husband or wife - unless it's confirmed what term they prefer to use.
- Where possible, it is more appropriate to have these conversations with the patient in private. Many people who are LGBTQ+, particularly those of the older generation, have not told their families about their sexual orientation or partner.
- If a person is considered to be nearing the end of their life and unable to leave the hospice/hospital then it's possible to organise a civil ceremony under the provisions of the Registrar General's Licence (RGL). (An RGL is a special legal provision allowing a marriage or civil partnership to take place at very short notice in circumstances where one of the parties is seriously ill and is not expected to recover.) (NB Restrictions can apply e.g. during Covid-19, so check the most up to date information online or discuss with the local Hospital Chaplaincy Team.)

3.5 Pregnancy and Maternity

General:

- If the patient is pregnant or a new parent, consider with them, and their partners/families if they wish, what specific support may be needed.
- Consider the needs of breastfeeding mothers, ask them what they need e.g. comfortable seat, pillow, a quiet corner, a glass of water.

3.6 Race

Be conscious of variances within all races, cultures and faith. Avoid making assumptions. Ask them to tell you what's important to them. For example, asking in a sensitive way may start with: How do you describe your ethnicity?

General good practice:

- Try to use appropriate terminology around race and ethnicity. Start by asking about a person's ethnicity (not race). Also, there are a number of terms for different ethnicities and nationalities, and different people will prefer and use different descriptors. It is best to take your lead from how a person describes themselves. For example 'black' vs 'Afro-Caribbean' or 'African Caribbean'.
- Avoid accidentally framing whiteness as the default position and Black and Ethnic Minority as deviant from this. For example, you should completely avoid using unacceptable words like "exotic" or "non-white".
- Try to be specific when referring to someone's nationality or race – terms like 'Asian' or 'African' cover a huge geographical area and therefore erase the diversity of different countries and ethnicities. So, for example, they might be more specifically described as Pakistani (rather than Asian).
- 'Mixed ethnic background' is the currently suggested term (replacing the previous 'mixed race' term).
- Use the term 'immigrant' correctly and carefully. Immigrants are people who move to live to a new country as individuals or a family. Often 'immigrant' is used to mark people of Black and Minority Ethnicities who are British nationals out as different.

To understand more about 'What exactly is a refugee, an asylum-seeker and a migrant?' see Appendix 3.

See section 4 for guidance on language and interpretation support.

Gypsy, Roma and Traveller communities

In hospital:

- Most Gypsies, Roma and Travellers tend to maintain high levels of cleanliness to prevent cross contamination and may worry about not being able to maintain this level of cleanliness in a hospital setting.

In the last hours of life:

- For many it will be important that a candle be lit near the bed of the dying person and kept alight.

After death:

- The community will often wish to have a funeral very soon after the death. Therefore, there may be a need to release the body quickly.

Refugee and Asylum Seekers

- The dying person and their family may lack trust in agencies as a result of their previous experiences. Showing sensitiveness and empathy may help develop their trust.
- The dying person and their family may lack awareness/understanding of palliative care.
- Language and communication issues may need to be addressed - see section 4
- Take care in identifying and understanding cultural, religious and/or health beliefs and preferences. There is a danger of misunderstanding between care recipient and the healthcare professional - see section 3.

3.7 Religion, belief and non-belief

We live in a multi-faith dynamic world of different faiths, cultures, races and traditions.

Responding to these needs will help ensure we deliver holistic care. Although not included in this document, as this doesn't usually change in the last days of life, dietary considerations can form part of a person's religion and beliefs. These considerations will also affect what is acceptable or not to the person.

This section presents a general picture of what *could* be needed. See Appendix 4 for more in-depth information about each of the most prominent religions / beliefs / non-beliefs in Wales (World Atlas). However, asking the person (or their family / carer) is the only way to know how they interpret / live by their own beliefs.

General considerations about religion/faith:

- Ask sensitively if the patient has any particular faith, religion or beliefs. Avoid making assumptions - ask what's important to them regarding this, in their last days/hours of life.
- If appropriate, ask the patient if they would like a visit from a representative of their faith and whether they have a local religious leader they would prefer to come, if they can.
- Where someone identifies as non-religious they do, of course, still have spiritual and emotional needs, as well as a moral framework that guides their life. These needs should be explicitly acknowledged and efforts made so the person does not miss out on pastoral care/support. For most, the source of this will not be a chaplain of faith,

but instead some hospitals and hospices have volunteers or staff who fulfil such a role. Some of these volunteers form part of a wider inter-faith or spiritual team and so may be accessed via the Hospital Chaplaincy. (See also Further Information section 5.)

- Some religions may express culturally based concerns about being treated by healthcare staff of the opposite sex. (See section 3.8.)
- Healthcare staff should try to be as accommodating as possible to large groups of visitors, extended family networks and the need for prayer space.

Source of further advice and support:

There is usually a 24/7 dedicated chaplaincy / multi-faith team who can support and advise healthcare staff on all aspects of different faiths and traditions. They will welcome your enquiry. Please contact them via your local DGH switchboard. More multi-faith information is also available on the Health Board intranet site.

3.8 Sex

General:

- Ask the person how they would like to be referred to. Be sensitive to the potential of needing to use different pronouns in response to gender self-identification. (See also Gender reassignment section 3.3.)
- Patients may prefer to be treated by a person of the same sex, if this is possible. However, if it's not possible, explaining why it's not possible is important. It's also important to be open to the possibility that they may feel uncomfortable or less comfortable with the opposite sex treating them, especially if it relates to some aspect of personal care. If so, this also needs to be acknowledged.

3.9 Sexual Orientation

General:

- Where ever possible, have these discussions in private – see section 1.
- When discussing those important to the patient and next of kin, use inclusive language such as 'partner' not husband or wife - unless confirmed what term they prefer to use.

3.10 Welsh Language - Preferred language/communication (Welsh Language Standards in accordance with the Welsh Language (Wales) Measure (2011))

General:

- In Wales, Welsh and English have official status. The Measure requires the use of the Welsh language to be enabled, encouraged and supported at every opportunity.
- In the last days of life, people tend to automatically revert or want to revert back to and feel most comfortable speaking their own mother tongue. They will also feel most comforted and reassured hearing their mother tongue spoken to them and around them. Please ensure that the patient's language choice is recorded in their notes / in the Care Decisions Guidance (Document A), and ensure that a Welsh speaking carer is then allocated to provide their care. Even a little Welsh can go a long way to calm and reassure patients and to connect with them on their own terms.

3.11 Socio-economic disadvantage (Duty)

General:

- In accordance with the 'The Equality Act (Authorities subject to the Socio-economic Inequality Duty) (Wales) Regulations 2021' consideration must be given to levelling up people's opportunities and avoiding them being disadvantaged or excluded because of living in less favourable social and economic circumstances than others

in the same society. In other words, we must take action to address inequalities that result from differences in occupation, education, where they live or social class. We are all responsible for helping to reduce inequalities associated with disadvantage and how they impact on people. So, we need to be sensitive in what we say and do. Good advice is to make no assumptions and to facilitate people who are experiencing social or economic disadvantage to have equal access to things at every opportunity. This does not mean treating everyone the same – see section 2.

- Some people e.g. the dying person's family/friends may not have access to a computer and broadband or smart phone. This will prevent them from accessing information to inform their decisions or to follow up your signposting e.g. to bereavement support. In this case you may need to print information for them. During Covid-19, being able to see someone on screen has also proved invaluable but also inaccessible for some.
- The cost of travel to visit someone who is dying in hospital or hospice can be more than what some can afford. A sensitive way of asking is: 'How are you planning to travel and is that manageable and affordable for you?' A flexible enabling approach is needed in these circumstances. Some may need additional support to help with visiting. The National Health Service (Travelling Expenses and Remission of Charges) (Wales) Regulations 2007 makes provision for people in receipt of certain benefits or low income to claim back certain charges and travel expenses to hospital. Those who may be entitled (including carers, family members and the patients themselves) should be signposted to the Health Board's Finance Department and/or a copy of the relevant procedure to ensure they are not socio-economically disadvantaged and are supported where possible.

4. Language translation and interpretation support:

For Welsh see 3.10 above.

- As an immediate response, ask amongst your colleagues as they may have additional language skills unknown to you. If a bi-lingual healthcare professional is not available, a registered interpreter should be contacted.
- Access to interpreters or translators by phone or face to face (including British Sign Language) can be requested through Wales Interpretation and Translation Service (WITS): 02920 537555, Email: WITS@cardiff.gov.uk or visit the website: <http://wits.wales/#1d> This service is available 24/7 and 365 days per year.
- There is usually very useful information about working with (or without) interpreters and translators on your Health Board intranet site.
- Translation by family members, however well meaning, can be complex and should not be the norm as this can compromise patient confidentiality, clinical privacy and may raise issues of consent. (See above.)

5. Acknowledgement and Further Information:

This resource has been informed from several valuable sources including:

- Amnesty International for definitions of a refugee, an asylum-seeker and a migrant (see Appendix 3) [Refugees, Asylum-seekers and Migrants | Amnesty International](#)
- BCUHB Spiritual Care Team Information (accessed March 2021 via BCUHB intranet) 'Supporting and delivering compassionate care'.
- BCUHB Spiritual Care Team Information (accessed March 2021 via BCUHB intranet) multi-faith information sheets.
- Deafblindness management information 2018 - accessed via NHS website April 2021 www.nhs.uk/conditions/deafblindness/treatment

- Faith at End of Life (2016), Public Health England
- Humanist Care: Pastoral care for non-religious people: [Non-religious people \(humanistcare.org.uk\)](http://humanistcare.org.uk)
- It's just good care: A guide for health staff caring for people who are trans* Public Health Wales
<http://howis.wales.nhs.uk/sitesplus/documents/861/It%27s%20Just%20Good%20Care.pdf>
- Learning Difficulties & EOLC: <https://www.pcpld.org/links-and-resources/>
- Non-religious Pastoral Support Network: <https://nrpsn.org.uk/areas-of-work/>
- Spirituality why it matters? spiritualcaremattersfinal.pdf (scot.nhs.uk)
- Social Model of Disability (accessed via Welsh Government website)

Further Acknowledgement - Thank you to all who have helped us produce this resource by sharing their expertise and insight. These include:

- BCUHB Equalities Team
 - BCUHB Spiritual Care Team Chaplaincy
 - BCUHB Welsh Language Service Team
 - British Heart Foundation
 - Compassionate Cymru
 - Compassion in Dying (Cymru)
 - Hospice UK (Wales)
 - Marie Curie (UK & Wales)
 - Marie Curie (Wales) Roundtable Users Group
- (Others were invited but the pandemic and other constraints were a barrier at the time.)

Other useful resources:

- Multi-faith and non-religious prayers and poems for End of Life: A resource for chaplains, family members, friends and members of the healthcare team, Buckinghamshire NHS Trust Microsoft Word - EOL Multifaith Resource BHT.docx (buckshealthcare.nhs.uk)
- A multi-faith resource for healthcare staff NHS Education Scotland: Final new Judaism section.indd (scot.nhs.uk)

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This Appendix to the Care Decisions Guidance was produced by the All Wales Care Decisions for the Last Days of Life Team.

If you have any comments, suggestions to add further useful information or require more information about this document or Care Decisions for the Last Days of Life in general, please contact us: Care.Decisions@wales.nhs.uk

Summary of the Equality Act 2010

Extract from the Equality Act 2010

In summary, those subject to the equality duty must, in the exercise of their functions, have due regard to the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act.
- Advance equality of opportunity between people who share a protected characteristic and those who do not.
- Foster good relations between people who share a protected characteristic and those who do not.

These are sometimes referred to as the three aims or arms of the general equality duty. The Act explains that having due regard for advancing equality involves:

- Removing or minimising disadvantages suffered by people due to their protected characteristics.
- Taking steps to meet the needs of people from protected groups where these are different from the needs of other people.
- Encouraging people from protected groups to participate in public life or in other activities where their participation is disproportionately low

Social Model of Disability

The Social Model of Disability is a way of viewing the world that was developed by disabled people in the early 1970s, adopted by Welsh Government in 2002, and enshrined in law in the DDA in 2005. It says that disability is caused by the way society is organised, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for disabled people.

The Social Model of Disability identifies systemic barriers, negative attitudes and exclusion by society that mean society is the main contributory factor in disabling people.

The Social Model shifts the focus away from individuals' impairments or conditions and instead looks at discriminatory barriers, whether physical, organisational or attitudinal, created and maintained by society. This rights-based approach helps develop positive attitudes in society.

Social Model Language

Note: This is not meant to be a prescriptive approach to language and must always recognise and respect the right of the individual to self-define how they wish to be addressed.

| Social Model Language: | Suggested <u>not</u> to use: |
|--|---------------------------------------|
| disabled person | person with disabilities |
| non-disabled person | able-bodied person / normal |
| physical impairment | physical disability |
| wheelchair user | wheelchair-bound / confined to |
| specific requirements | special needs |
| additional learning requirements | special educational needs |
| person with cancer / HIV etc. | person suffering from . . . |
| sensory impairment / communication impairment | deaf and dumb |
| cognitive impairment / learning impairment [could also use learning difficulty but not so comprehensive] | learning disability |
| person with epilepsy | epileptic |
| mental health issues | mentally ill / mental health problems |
| person with autism or on the autism spectrum or neuro-diverse person [some people on the spectrum also choose the terms 'autist'] | autistic |
| social support [disabled people have insisted that they neither need nor want to be "cared for". People just want support to live the lives they choose] | social care |
| support worker / Personal Assistant [Following the legal definition of a Carer as unpaid in the 2014 Act it is no longer appropriate to refer to paid staff as 'carers' or 'care workers'] | carer / care worker |
| Service recipient / person / individual / citizen | Service user / user |
| sign language interpreter [spoken language is interpreted – written text is translated] | Signer / translator |
| accessible toilet, parking, facilities | disabled toilet, parking, facilities |
| Blind / visually impaired people | the blind |
| Ddeaf people [the extra capital D recognises that some people without hearing who use sign language see themselves as members of a linguistic community and not as sensory impaired] | the deaf |

What exactly is a refugee, an asylum-seeker and a migrant?

Source: Amnesty International: [Refugees, Asylum-seekers and Migrants](#)

- The terms “refugee”, “asylum-seeker” and “migrant” are used to describe people who are on the move, who have left their countries and have crossed borders.
- The terms “migrant” and “refugee” are often used interchangeably but it is important to distinguish between them as there is a legal difference.

Definitions:

Who is a refugee?

- A refugee is a person who has fled their own country because they are at risk of serious human rights violations and persecution there. The risks to their safety and life were so great that they felt they had no choice but to leave and seek safety outside their country because their own government cannot or will not protect them from those dangers. Refugees have a right to international protection.

Who is an asylum-seeker?

- An asylum-seeker is a person who has left their country and is seeking protection from persecution and serious human rights violations in another country, but who hasn't yet been legally recognized as a refugee and is waiting to receive a decision on their asylum claim. Seeking asylum is a human right. This means everyone should be allowed to enter another country to seek asylum.

Who is a migrant?

- There is no internationally accepted legal definition of a migrant. Like most agencies and organisations, Amnesty International understand migrants to be people staying outside their country of origin, who are not asylum-seekers or refugees.
- Some migrants leave their country because they want to work, study or join family, for example. Others feel they must leave because of poverty, political unrest, gang violence, natural disasters or other serious circumstances that exist there.
- Lots of people don't fit the legal definition of a refugee but could nevertheless be in danger if they went home.
- It is important to understand that, just because migrants do not flee persecution, they are still entitled to have all their human rights protected and respected, regardless of the status they have in the country they moved to. Governments must protect all migrants from racist and xenophobic violence, exploitation and forced labour. Migrants should never be detained or forced to return to their countries without a legitimate reason.

Religion, belief and non-belief – Detail Section

This list is based on the current most prominent beliefs/non-beliefs in Wales.

As this resource forms part of the All Wales Care Decisions Guidance, information related to the **last days or hours of life only** is presented. Alongside this, where known about, any special requirements for the body at time or very soon after death is also noted as healthcare staff may be required to act appropriately without family members present, as experienced during the Covid-19 pandemic. See Further Information section for links to wider information, if required.

Contents in alphabetical order:

- Agnostic
- Buddhism
- Christian (including: Anglican, Roman Catholic, Free Church)
- Druidism
- Hinduism
- Humanist / Atheist
- Islam
- Jehovah's Witness
- Judaism
- Pagan
- Quaker
- Sikhism

NB. This information will apply to most in these categories but not all followers adopt the same customs so it's important to ask what's important to them.

Agnostic (non-belief)

In last few days of life:

- In facing this situation, some may wish to revisit their childhood/previous religion or belief
- Some may seek a new spiritual context, possibly exploring their own symbolism and narrative.

Atheist – see Humanist

Buddhism

In last few days of life:

- Most Buddhists prefer to know they are dying because it allows mental and spiritual preparation.
- Pain management may be a sensitive topic.
- Healthcare professions should refrain from any display of emotions or behaviour that will disturb the individual's state of mind.

After death:

- For most Buddhists, to accommodate spiritual practise, the body should be kept as still as possible and avoid disturbances during transport.
- Family members may request that the body is not touched and that it's available to them to perform religious rites.

Christianity

Church of England / Wales: Anglican

In last hours of life:

- Some Anglicans may ask to receive Holy Communion and/or be anointed.

Roman Catholics

In last hours of life:

- 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.

Free Churches

In last hours of life:

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

Druidism

At the point of death / after death:

- For most Druids the sacred rite of passing is often varied and may be conducted imminently after death, dependent on the individual's wishes.
- The rite is written to be led by a celebrant, a priest who ensures that all that must be done is done, holds the energy and the sanctity of time and place. However, it may be facilitated less formally, simply by one who is organising the event.

Hinduism

In last few days of life:

- For most Hindus, family must be consulted to see if they wish to carry out last rites or distress can be caused if the body is touched by non-Hindus.
- Constipation can be a major silent illness that needs to be sensitively approached.
- Personal or religious objects, Ganges water and religious texts (including prayer or readings) may be used.

In last hours of life:

- Physical and spiritual purity is important for most Hindus, and some require the use of water for ablutions (ceremonial cleansing).
- Shortly before death, the person may want both the sacred tulasi leaf and Ganges water administered to the dying person by their family or a priest. Ideally this should be done as close to death as possible.

After death:

- When family is not available, it's important that healthcare staff close the eyes of deceased, straighten their limbs, ensure jewellery and religious objects are not removed and the body is wrapped in a plain white sheet.

Humanist / Atheist

In last few days of life:

- Most Humanists or Atheists believe in the sanctity of life but not in the existence of a higher being so will not want any prayers offered or references made to God.

Islam

In last few days of life:

- For most Muslims, decision-making may be collective and involve the whole family. Most families of a dying person may therefore request information and involvement in the decision-making process.
- Patients may continue to observe strict dietary (halal) rules.

In last hours of life:

- Patients may require help to perform ablutions (ceremonial cleansing).
- The patient may wish to lie or sit facing towards Mecca (Qibla, to the South East in the UK).

After death:

- Following death, Muslims may request that the body faces Mecca, with their eyes and mouth closed and the limbs straightened.
- Family members may feel uncomfortable for the body to be touched by healthcare staff, so contact should be kept to a minimum to perform the Ghusl.
- A white shroud will be used to wrap the body.
- The majority of Muslims do not wish a post-mortem to be carried out unless required by law.
- 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.

Judaism

In last few days of life:

- Patients may continue to observe strict dietary rules.
- Most orthodox Jews will continue to observe the Sabbath and strict kosher dietary rules.

In last hours of life:

- For most Jews, the dying person should not be left alone and it's customary for families to arrange a 'watcher' to guard the body after death.
- As the last stages of life approach, most Jews may wish that a Rabbi is informed so they can call upon the Holy Society to perform burial rites.

After death:

- After death is confirmed the eyes should be closed and the body 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.
- Jewish tradition encourages burial as soon as possible and should take place within 24 hours after death.

Jehovah's Witness

In the last few days of life:

- For most Jehovah's Witnesses, congregational support is important and a dying patient may receive a number of visitors. If this causes difficulties for the patient it may be possible to talk to the visiting Elder to ask for help in regulating visitors.

In the last few hours of life:

- For most, there is no formal religious ritual as a person is dying, but the opportunity for quiet private prayer with a local Elder may be appreciated.
- Last Offices are performed as normal, unless the family have special wishes.

After death:

- The body should be wrapped in a plain sheet. There is no religious prohibition against post-mortem, but most Jehovah Witnesses refuse them if there is no legal requirement. There is no religious prohibition against organ donation.

Pagan

In the last few days of life:

- Most Pagans will want to know they are dying so they can prepare positively for death.
- As there are many diverse traditions within paganism, you should ask the patient if they have any special requirements.
- Physical and symbolic changes in the room may be wanted to help trigger the four senses.

At the point of death:

- Their invited chaplain or spiritual leader may wish to take them on a guided meditation to that place where they expect to meet their spiritual or family member.

After death:

- For most Pagans, the body is washed and anointed with water and three drops of oil, usually frankincense, myrrh and another such as sage.
- At this point their chakra points are closed down, from the root chakra up to but not including the crown chakra. This is done by an anticlockwise motion of the hand over

the given area starting at the outer edges of the aura bringing it down just above the surface.

- Prayers and readings are spoken as appropriate and then the deceased person is placed into a winding sheet or shroud or clothed in their robes or best attire ready to meet their deity.

Quaker

In the last few days of life:

- A Quaker may want the Clerk of the Friends Meeting House where they attend to know that they are dying if they require spiritual support. Privacy would be appreciated for this visit, if possible.

Sikhism

In last hours of life:

- For most Sikhs, in a situation where the family cannot perform the recital of hymns, a Granthi (Sikh Priest) may be asked to step in and recite prayers. In the absence of a Granthi, a recording of the Sikh scriptures should be playing close to the dying person.

After death:

- If the patient dies when the family are not present, healthcare staff should contact family immediately.
- Healthcare staff should aim to release the body promptly to enable the body to be cremated.

If you have not found the religion or belief you are seeking or would like wider information, see the Further Information or Other Useful Resource in section 5.