The Care Certificate was introduced in 2015 to ensure that all social care and healthcare workers have the knowledge, skills and behaviours to provide compassionate, safe and high-quality care and support.

Some of the standards have been contextualised to different working situations or services to help new workers, or workers new to a particular area of care, to apply the content to their specific roles.

The Care Certificate has been contextualised into six areas:

- austism
- dementia
- end of life care
- learning disability
- lone working
- mental health

This document includes the contextualised standards.

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This resource doesn't cover all of the Care Certificate standards as not all need contextualising, some are universal and apply in the same way to all areas of work. For example, 'Standard 12 Basic life support' applies in the same way to all areas of care.

This resource is and designed to be used in to, and to , current Care Certificate delivery and resources, such as the Care Certificate workbooks and presentations. Required additional and specialist learning should be based on the 'End of life core skills education and training framework' which outlines the core skills and knowledge that staff need to support people at the end of their life.

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is designed to support workers new to this area to help contextualise the content of Care Certificate to their role. The resource can be used by learners, Care Certificate trainers and assessors.

is not a mandatory resource. It can be used in a number of ways, by a number of people, to enhance current Care Certificate learning and development. There are activities included throughout. These could be completed verbally or written down or adapted to be included within a trainer's or assessor's other resources.

The resource could be used:

- in group learning environments, face-to-face or virtually
-

Doris lives in her own home and currently receives home care visits twice a day. Doris now needs additional care as she is approaching the end of her life and has requested to stay at home.

- What different and additional types of support could Doris now require?
- How would you promote good partnerships with others who become involved in Doris's end-of-life care?
- What will the benefits be of working in partnership with others in this scenario?

Partnerships also include the team in which you work. Communicating regularly with your team will help you all provide the best possible care and support.

Mary is approaching the end of her life. The care team become aware that her pain
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Jim lives in a care home and is at the end of his life. Jim has started to become disorientated and may be at risk of falling. Following a care plan review, reasons for this are discussed in detail. Jim likes to move about a lot and wants to be active. This is presenting a dilemma for his care team as he may not be safe.

The care team supports Jim with the following actions to enable him to remain as active as possible in the safest way. The team:

- carries out a risk assessment which helps to identify situations and times when Jim is most at risk of falling
- provides extra staff support to Jim during situations and times when it's identified that he's at high risk of falling.

The home manager:

- makes a referral to the falls clinic (the falls clinic carries out specific assessments and can recommend equipment)
- carries out regular reviews of Jim's health and wellbeing to monitor his progress and shares them as appropriate with other professionals involved in his care.

Isabella has moved from her family home into a care home with nursing as her health has deteriorated and she now needs nursing care. Her parents haven't told Isabella that she has a life-limiting illness and they request that Isabella isn't told this. Isabella is 30 years old. It's clear that Isabella has full mental capacity and believes the care home is going to make her better.

- Why could this situation cause confrontation?
- Who could provide support in this situation?

The care team decides it's in Isabella's best interests for her to know she's approaching the end of her life.

This is a difficult situation and presents a dilemma in Isabella's care.

- What approaches could be used to support Isabella and her parents?

- NICE quality standard which covers care for adults (aged 18 and over) who are approaching the end of their life.
- What to expect from end of life care
- Mental capacity

People at the end of their life may experience discrimination. Discrimination against a person approaching the end of their life occurs when a person, or organisation treats that individual unfairly because they're dying or because of something associated with this. Others can sometimes make assumptions about the person's abilities and needs and treat them very differently to how they would have treated the person when they were well.

Aisha has lived in a care home for five years. Aisha's illness has now progressed and she's approaching the end of her life. Aisha has always contributed to the home by chairing the residents' meeting. Plans for the home are often discussed during the meeting. The staff team inform Aisha that she can no longer chair the meeting and isn't able to contribute to future plans of the home.

Aisha now needs mobility support to get to the meeting location, but there aren't enough staff working to assist her to the meeting location at the required time.

You need to recognise if or when someone you're supporting is being discriminated against and know how to challenge discrimination. You'll need to remember that the person you're caring for may or may not want you to challenge it, may want to challenge it themselves or be offered access to an independent organisation which can help them. Your role is to support the person to be heard and to enable choice and control about their care and support needs. Sometimes others can stereotype and display certain attitudes which can present challenges in the way care is agreed and provided.

Supporting a person approaching the end of their life will involve enabling them to have equal opportunities – so that any required adaptions, needs and wishes are listened to, can be met

Knowing a person's religious, spiritual or cultural beliefs in relation to death and dying is very important in respecting what matters to the person and those important to them. Knowing this is on their advance care plan can provide great comfort and promote the individual's spiritual wellbeing. It's important to recognise that some people's beliefs and wishes may change as they approach the end of their life. For example, a person may develop religious beliefs as they approach the end of their life or another may lose faith in their religious beliefs. These decisions should be respected and noted in the advance care plan.

Norman is now receiving some care and support from a local hospice. As Norman's care needs have increased, he's worried about losing the ability to make his own decisions.

## 5

Each person you care for is unique. You'll need to continue to recognise, respect and respond to the individual needs, wishes and feelings of the person as they approach the end of their life - just as you would at any other time.

It's your role to enable the person to live well until they die. This may include empowering people to make decisions about their care and support, as their needs, wishes and feelings change.

An advance care plan (ACP) is in addition to an individual's care plan. It helps to make clear a person's wishes and preferences about their end of life care.

Along with the individual, different professionals and the person's family are likely be involved in planning, delivering and reviewing the ACP.

It's important for individuals to develop an ACP as early as possible so their wishes can be implemented, even if their capacity to express those wishes is reduced.

Rhea has been diagnosed with a life-limiting condition. For Rhea to express what's important to her, the care team suggest developing an ACP with her. The care team introduce the ACP to Rhea by:

- providing information to Rhea in a sensitive way
- providing information to Rhea in way that she can understand
- supporting Rhea to make an informed choice about her wishes to have an ACP
- asking if there are others that Rhea wants to be involved such as loved ones, family and friends
- asking Rhea and suggesting relevant healthcare professionals who could be involved in the process
- explaining to Rhea how the team and others could support her to develop her ACP.

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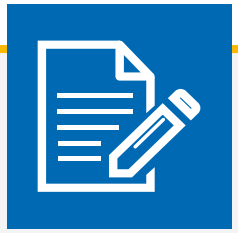
- Check your organisation's process on advance care planning. How could you support Rhea to contribute to her ACP?



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Considering the person's wishes, needs and preferences will help you to create an environment which can enhance their comfort at the end of their life. Different people will find different environments comforting at different times, but some considerations might include:

- providing opportunities for the person to talk and to express their needs in private or with other people
- environmental considerations such as comfort areas, places to be alone or to be with family, friends and other people. Specifically, this could cover lighting, seating areas, noise and temperature, privacy, indoor and outside spaces and access
- helping the person to enjoy their favourite hobbies or interests. These may need to be adapted as appropriate
- personal items which the individual can see such as photos and pictures
- enabling the person to take part in meaningful activity. This could include holistic therapies such as aromatherapy, meditation, relaxation techniques
- choice of music, radio or silence in line with the preference of the individual
- preferences of the individual, such as enjoying listening to talking books.

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Managing pain and ensuring people are comfortable as they approach the end of their life is a very important part of their care.

To support people with managing their pain and comfort levels, you should ask the individual if they're in any pain or discomfort. You could also ask them to describe the level of pain they're experiencing. You may need to observe or look for signs of discomfort being displayed by the person such as:

- facial expressions such as frowning or grimacing
- moaning and calling out
- flinching when touched
- restlessness and agitation
- being withdrawn and quiet.

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## Identity

Our identity is what makes us unique and is our sense of who we are. It encompasses personality, spirituality, sexuality, values and culture and is built from our beliefs and experiences.

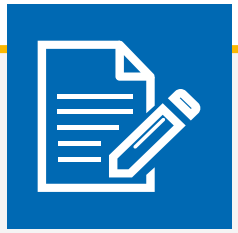
A person approaching the end of their life may become unable to share their experiences, life history and preferences. Understanding someone's ACP and maintaining communication with appropriate others can help you support their wishes, enabling them to hold onto what makes them who they are and maintain a sense of self and purpose.

Aisha recently moved into the care home to receive end of life care. Aisha is a devout Muslim and feels this is an extremely important part of her identity.

When Aisha moved into the care home, she was involved in developing her care plan and ACP. Aisha identified that she can only eat halal meat, that she needs privacy within her room when she prays five times a day and that she would prefer to receive personal care by female workers only.

Aisha's wishes have been respected and Aisha feels very comfortable and confident within the care home.

Aisha has stipulated who she wishes to be told if her condition deteriorates and knows that staff understand that when she dies, she wants her sister to wash and prepare her body rather than the staff in the care home. This information is clearly recorded in Aisha's ACP and has been discussed with her sister.



As Aisha comes to the end of the life, she informs you she wants to make changes to her wishes in her ACP.

- How would you respond to Aisha?

## Resources

- Skills for Care end of life care resources and webinars
- Dying Matters
- Dying Matters: My funeral wishes

Communicating with the person approaching the end of their life is an essential and crucial part of delivering person-centred compassionate care.

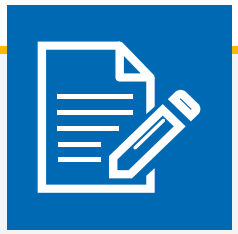
The person may have difficulty in being able to communicate with others. For example, they may:

- be in pain or discomfort
- be affected by medication
- be unable to verbally respond
- have impaired eyesight or hearing
- have an illness or condition which affects their ability to communicate
- have a disability which affects their ability to communicate
- have been impacted emotionally by their situation
-

Mabel has just moved into a different area of the care home as she approaches the end of her life. This is your first time providing care for Mabel and when you greet her, she appears very upset. She explains it feels very different in her new room and she doesn't know any of the carers.

You listen and talk to Mabel, adapting your communication skills to reassure and help her understand why she's now in a different part of the care home. This includes:

- introducing yourself and explaining why you're there
- sitting facing Mabel and providing good eye contact without overwhelming her
- listening to Mabel to show you are interested and want to help
- talking through her worries, providing reassurance and assistance if required.



Hugo is approaching the end of his life and asks you some complicated questions about the medication he is receiving.

- How would you respond to Hugo?
- Who might you need to seek some help from?
- How could you ensure information is provided to Hugo in a way he understands?

## 7.2b

Each person you care for is unique and individual. As a person approaches the end of their life and after they've passed away you need to continue to recognise, respect and respond to the individual's privacy and dignity needs, just as you would at any other time of their life.

In addition to the examples provided in 7.2b of the Care Certificate, promoting someone's privacy and dignity during and at the end of their life, could also include understanding, supporting and respecting their:

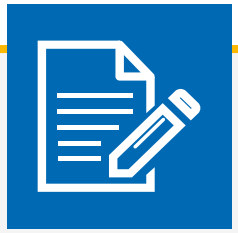
- own personal space and providing this when they request it
- personal information and how they wish for it be shared
- religion, culture, beliefs and traditions
- spiritual needs
- lifestyle and environment choices and preferences
- rights and choice to have social and personal relationships
- need for time, space and support to maintain social and personal relationships (including intimate and sexual relationships)
- preferences with personal appearance.

You'll also need to compassionately support the privacy and dignity needs of family/friends and loved ones when they visit or spend time with the person approaching the end of their life. It can be a difficult time for those involved in the person's life and they may feel isolated and vulnerable.

Sangita is approaching the end of her life and lives at home. A relative has called and arranged to visit Sangita. To support the visit you:

- ask Sangita if there are any preparations she'd like support with before and during the visit
- ask Sangita if she'd like support with her personal appearance
- check the environment is comfortable with a space to sit
- greet the relative when they arrive
- respect their privacy whilst they meet, and explain where you are if needed
- provide opportunity for the relative to talk to you if needed, being mindful of Sangita's privacy and not disclosing any confidential information without consent.

These actions meant you supported Sangita and her relative to meet in a way which maintained their privacy and upheld Sangita's dignity.



Patrick is experiencing some health complications as he approaches the end of his life. An ambulance is called and arrives at the care home. Others who live in the care home are asking questions, such as “who is the ambulance for?” and “why is the ambulance here?”.

- How could you respond to and reassure others who live in the care home without compromising the privacy and dignity of Patrick?

As a person approaches the end of their life, they should be supported to retain as much choice and control as possible. This will include being able to make informed choices about their life, the care they receive and decisions around supporting them to have a good death. The person may need additional support with this which may include adapting the communication approaches used with the person.

The ACP is an important tool which helps to make clear a person’s wishes and preferences about their end of life care. The use of the ACP will help and support the person to maintain their choices and control if/when they’re unable to state or make decisions at the end of their life.

Advanced decisions can also be made regarding treatments and interventions the egarding5 (e5 507

An individual with mental capacity can appoint a power of attorney. This is a legal arrangement that a person can make and allows the person with the power of attorney to make decisions on the individual's behalf. There are two different types granted and a person can have one or both of the following:

- health and welfare – can only make decisions relating to health and welfare
- property and financial affairs – can only make decisions relating to property and financial affairs.

Also, relevant here is The

Other professionals can provide support for an individual who is struggling to eat and drink including:

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John is approaching the end of his life and requires assistance with eating and drinking. Until now John has managed to eat well when you place cut-up food onto a spoon and place it into his mouth.
When supporting John today, you notice that he starts coughing and attempts to spit out the food.

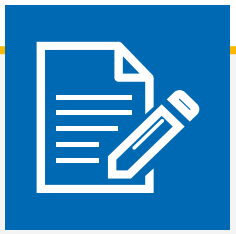
- When should you report and record the changes you have observed?
- Why should you report the changes you have observed?
- How would you reassure John?

## 13



A person at the end of their life may experience sudden illness, deterioration and additional symptoms associated with or in addition to a diagnosed illness. You need to be familiar with and adhere to your organisation's procedures when responding to accidents, sudden illness and changes in the person's needs.

As explored in standards 5 and 7 of this resource, the individual may have an in place, along with any and/or / they've made. It's important to know the decisions a person has made, where this information is stored and how it can be accessed and shared with relevant health professionals when responding to sudden illness.



Jim is receiving end of life care in a nursing home. You find Jim unresponsive and not breathing. Jim has an ACP in place and has made a DNAR/DNACPR decision:

- How would you respond to this situation, ensuring you're following your workplace procedures?
- Who might you need to share information with regarding Jim's ACP and DNAR/ DNACPR and why?

## A person who's at the end of their life may be prescribed additional medication and may require support with specific healthcare tasks. You'll need to understand, follow and implement guidance relating to your own responsibilities in line with your organisation's procedures, and as directed in the person's care plan and ACP.

Other professionals, such as the GP, district nursing team and palliative care teams, are likely to be involved with the individual's care. They may be involved in providing medication and carrying out specific healthcare tasks. For example, the person may be prescribed anticipatory medication which can only be administered by the district nurse. If other professionals are involved in the individual's care, then information about this will be in the person's care plan and ACP.

In line with your organisation's agreed ways of working, you need to liaise professionally with those involved in the individual's care. This will help ensure that the person at the end of their life is fully supported and has their health needs met.

## Caring compassionately for a person who is at the end of their life is both a privilege, a responsibility and can be a rewarding and humbling experience. It's normal to feel anxious, pressured and worried about being prepared to support a person reaching the end of their life, especially if you've not experienced this before.

There are many ways you can access support including:

- additional learning and development opportunities which are available to you in your role
- supervision sessions with your line managers
- discussions and reflections on practice and approaches during team meetings, handovers and debrief sessions
- a workplace mentor or senior colleague
- other professionals also involved in the person's care such as palliative care teams, district nursing teams and the local hospice
- organisations recommended by your workplace who you can contact independently for advice and support, such as counselling services or employee helplines.

There are also many voluntary and charity organisations which can provide support for you and others involved in the person's care and life such as: MIND, Sue Ryder, The Good Grief Trust, Cruse Bereavement Care and Hospice UK.

Understanding the person's needs, wishes and feelings and your professional boundaries in the care that you provide is fundamental in supporting your emotional wellbeing. It's normal to feel upset when a person is at the end of their life and you should try and manage this in a professional way.

Managing your own self-care, such as having a good work/life balance and physical and mindfulness activities are important and will help to manage your own stress and wellbeing in your role.

An important aspect of delivering good, effective care and support to people at the end of their life will be teamwork. Working as a team with your colleagues and supporting each other will be fundamental in this.

- Skills for Care end of life care resources/working together to improve end of life care
- e-ELCA (e-learning programme end of life care for all)
- End of life care

Before working in any environment, you should be aware of what activity and infection prevention measures you're likely to need to carry out and plan how to reduce associated risks. There'll be additional precautions and procedures which you need to follow. For example, when:

- the person you're caring for has a low immune system, which makes them more susceptible to infection
- the person has an infectious disease
- you contribute to the care of a deceased person.

You must work in line with methods outlined in your agreed way of working and local policies.

This work was made possible through the involvement of the following organisations and people:

Wakefield Hospice
Calderdale and Huddersfield NHS Trust
Sheffield Teaching Hospitals NHS Trust
Dove House Hospice
Community Palliative Care Team, Shipley Medical Centre

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