National Unit Specification

General information

Unit title: Care in the Last Days of Life (SCQF level 6)

Unit code: J473 46

Superclass:	PA
Publication date:	May 2020
Source:	Scottish Qualifications Authority
Version:	completed by SQA

Unit purpose

This unit is designed to enable learners to develop their knowledge and understanding of end of life care. The unit will examine the dying process and common conditions experienced at the end of life. In addition, the importance of communication in the last days of life and the promotion of choices and preferences will also be explored. This includes responding to the bereavement needs of the individual's family or significant others. Current ethical dilemmas surrounding decisions made in the last days of life will be examined together with the principles, legislation and guidelines that direct end of life care.

Outcomes

On successful completion of the unit the learner will be able to:

1   Describe the dying process including common symptoms experienced in the last days of life.
2   Explain the importance of effective communication in the promotion of choices and preferences of the individual, family and carers in the last days of life.
3   Explain ethical dilemmas that relate to decision making in the last days of life.
4   Describe how principles, legislation, policy and guidelines direct care when a person dies.

Credit points and level

1 National Unit credit at SCQF level 6 (6 SCQF credit points at SCQF level 6)

National Unit Specification: General information (cont)

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Recommended entry to the unit

Whilst access to the unit is at the discretion of the centre, it is recommended that learners have good communication skills, both written and oral.

Core Skills

There are opportunities to develop the following Core Skills:

♦ *Communication* at SCQF level 6
♦ *Information and Communication Technology (ICT)* at SCQF level 6
♦ *Numeracy* at SCQF level 6
♦ *Problem Solving* at SCQF level 6
♦ *Working with Others* at SCQF level 6

Opportunities to develop aspects of Core Skills are highlighted in the support notes for this unit specification.

There is no automatic certification of Core Skills or Core Skill components in this unit.

Context for delivery

If this unit is delivered as part of a group award, it is recommended that it should be taught and assessed within the subject area of the group award to which it contributes.

The Assessment Support Pack (ASP) for this unit provides assessment and marking guidelines that exemplify the national standard for achievement. It is a valid, reliable and practicable assessment. Centres wishing to develop their own assessments should refer to the ASP to ensure a comparable standard. A list of existing ASPs is available to download from SQA's website **(http://www.sqa.org.uk/sqa/46233.2769.html)**.

Equality and inclusion

This unit specification has been designed to ensure that there are no unnecessary barriers to learning or assessment. The individual needs of learners should be taken into account when planning learning experiences, selecting assessment methods or considering alternative evidence.

Further advice can be found on our website **www.sqa.org.uk/assessmentarrangements**.

National Unit Specification: Statement of standards

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Acceptable performance in this unit will be the satisfactory achievement of the standards set out in this part of the unit specification. All sections of the statement of standards are mandatory and cannot be altered without reference to SQA.

Outcome 1

Describe the dying process including common symptoms experienced in the last days of life.

Performance criteria

(a)   Describe the dying process and the uncertainties around death.
(b)   Describe the common symptoms experienced in the last days of life.
(c)   Describe the role support services play in caring for the dying person.

Outcome 2

Explain the importance of effective communication in the promotion of choices and preferences of the individual, family and carers in the last days of life.

Performance criteria

(a)   Explain the use of effective communication to demonstrate compassion and empathy in meeting the needs of the individual in the last days of life.
(b)   Explain the importance of information and support that the individual, family and carers need to engage in and be empowered by to state their choices and preferences.
(c)   Describe cultural beliefs that guide practices before and after death and the importance of maintaining respect and dignity when providing care.
(d)   Describe attitudes towards death and dying and the resultant behaviours.

Outcome 3

Explain ethical dilemmas that relate to decision making in the last days of life.

Performance criteria

(a)   Describe ethical dilemmas associated with the last days of life.
(b)   Explain the importance of advocacy and proxy decision making in the promotion of individual choices and preferences.

National Unit Specification: Statement of standards (cont)

Unit title: Care in the Last Days of Life (SCQF level 6)

Outcome 4

Describe how principles, legislation, policy and guidelines direct care when a person dies.

Performance criteria

(a)   Explain the principles and national and local policy and guidelines for end of life care and how these contribute to improving care.
(b)   Describe the carer's responsibilities in relation to end of life care.
(c)   Explain the legislation and processes for confirmation and certification of death.
(d)   Describe the practical issues that surround death and information and sources of support available locally.

Evidence requirements for this unit

Evidence is required to demonstrate that learners have achieved all outcomes and performance criteria.

Evidence can be gathered in a range of ways which will assess learners' knowledge, understanding, and application across the learning outcomes and performance criteria.

Where learners have worked in a group, there should be evidence of their individual contribution.

The Assessment Support Pack for this unit provides sample assessment material. Centres wishing to develop their own assessments should refer to the Assessment Support Pack to ensure a comparable standard.

Outcome 1

Describe the dying process including common symptoms experienced in the last days of life.

To achieve outcome 1 learners must produce evidence to show they can:

♦   describe three uncertainties around death.
♦   describe three common symptoms experienced in the last days of life.
♦   describe the role of two support services that may be involved at this time.

National Unit Specification: Statement of standards (cont)

Unit title: Care in the Last Days of Life (SCQF level 6)

Outcome 2

Explain the importance of effective communication in the promotion of choices and preferences of the individual, family and carers in the last days of life.

To achieve outcome 2 learners must produce evidence to show they can:

♦ explain the importance of two different types of information and support relating to the needs and empowerment of the individual, family and carers.
♦ describe how two cultural beliefs guide care and practice before and after death so that the respect and dignity of individuals is maintained.
♦ describe three ways that attitudes to death and dying can impact on behaviours.

Outcome 3

Explain ethical dilemmas that relate to decision making in the last days of life.

To achieve outcome 3 learners must produce evidence to show they can:

♦ describe four ethical dilemmas relating to the last days of life.
♦ explain two aspects of advocacy and proxy decision making that are pertinent to end of life choices and preferences.

Outcome 4

Describe how principles, legislation, policy and guidelines direct care when a person dies.

To achieve outcome 4 learners must produce evidence to show they can:

♦ describe the four national principles for end of life care and how they contribute to improving care.
♦ describe two responsibilities of the carer in relation to end of life care.
♦ describe two practical issues around the time of death and the sources of support available for friends and family in the local area.

National Unit Support Notes

Unit title: Care in the Last Days of Life (SCQF level 6)

Unit support notes are offered as guidance and are not mandatory.

While the exact time allocated to this unit is at the discretion of the centre, the notional design length is 40 hours.

Guidance on the content and context for this unit

This unit is a mandatory unit in the National Progression Award (NPA) Palliative and End of Life Care at SCQF level 6. The unit can also be studied on a stand-alone basis.

This unit is designed to enable learners to develop their knowledge and understanding of end of life care. The unit will examine the dying process and common conditions experienced at the end of life. In addition, the importance of communication in the last days of life and the promotion of choices and preferences will also be explored. This includes responding to the bereavement needs of the individual's family or significant others. Current ethical dilemmas surrounding decisions made in the last days of life will be examined together with the principles, legislation and guidelines that direct end of life care.

Outcome 1

The process of dying may involve any of the following:

♦   person's health continuing to deteriorate
♦   more physical changes in the person, eg:
    —   **sleeping more** — waken only for short periods for specific tasks
    —   **eating less** — poor appetite, metabolism slow, difficulty digesting food/swallowing and at risk of choking
    —   **difficulty using the toilet** — restricted mobility, lower urinary output, incontinence (urinary or faecal), constipation, diarrhoea, obstruction, stoma
    —   **changes in breathing** — rapid, shallow, noisy, cheyne-stoking
    —   **mobility changes** — inability to stand due to weakness/muscle wasting/level of consciousness/balance/previous injury or disease, eg stroke, fracture of limb
    —   **changes in their level of consciousness** — lack of oxygen and multi organ shut down
♦   need to put things right — emotional and spiritual care

The places people may receive end of life care:

♦   home
♦   acute care
♦   care homes/residential homes
♦   prisons
♦   homeless shelters
♦   hospice

National Unit Support Notes (cont)

Unit title: Care in the Last Days of Life (SCQF level 6)

A range of multidisciplinary team are involved in health and social care:

♦ social carers
♦ community and hospital nurses
♦ specialist nurses
♦ doctors
♦ allied health professionals
♦ community pharmacists
♦ hospice — delivering specialist advice, and care

The uncertainties around death may include:

♦ time/date of death are unpredictable
♦ no set process — individual to the person
♦ choices and preferences may not be met
♦ family may not carry on the caring role without support
♦ the place of death may be determined by the support services available in the person's locality

Most common symptoms occurring in the last days of life:

♦ pain (nerve, emotional, spiritual, physical)
♦ vomiting
♦ nausea
♦ weakness
♦ fatigue
♦ breathlessness
♦ constipation
♦ oral infections
♦ incontinence
♦ agitation/restlessness
♦ distress from hallucinations
♦ fear
♦ skin colour changes
♦ changes in mental agility
♦ causes of distress may include:
    — physical, eg uncontrolled pain and symptoms, body image, treatment regimes
    — emotional, eg family dynamics, regret, fear, sadness, anger, disbelief
    — spiritual, eg self-belief, values, culture
    — social, eg social exclusion, no family support, loneliness

Scottish palliative care guidelines — symptom control guidelines
http://www.palliativecareguidelines.scot.nhs.uk/guidelines/symptom-control.aspx

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Outcome 2

There are a range of communication models which can be utilised. Communication skills include:

♦ listening skills
♦ awareness of body language and non-verbal cues
♦ ability to summarise verbally what has been heard
♦ act and respond appropriately within own range of knowledge/skills
♦ ability to engage with people in an open, honest and sensitive manner
♦ engage with people in a way that respects their wishes, choices and confidentiality supported by a person centred culture
♦ awareness of own strengths and vulnerabilities and when to refer to another skilled practitioner
♦ request feedback to reflect on improvement needed in communication skills
♦ awareness of support available for self-care

Importance of information and support:

♦ empowers people with the ability to make decisions about what really matters to them
♦ gives knowledge and confidence to make the right decision for them
♦ allows the person to build on the information received and research further

Types of information and support people need to be empowered to state their choices and preferences include:

♦ time and a supportive team to listen and act on individual preferences
♦ anticipatory care planning
♦ power of attorney
♦ living wills
♦ Carers Act — need to identify main carer and assess their needs together with formulating an appropriate care plan and supporting their rights as a carer
♦ respite
♦ overnight care
♦ specialist treatment available
♦ specialist teams available locally
♦ awareness of Human Rights Act

Cultural and faith beliefs that guide practice before and after death:
http://www.nes.scot.nhs.uk/media/3720/march07finalversions.pdf.pdf

Attitudes towards death and dying and resultant behaviours:
http://www.bsa.natcen.ac.uk/media/38850/bsa_30_dying.pdf
https://spcare.bmj.com/content/3/1/37

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Resultant behaviours:

♦   Negative:
   —   death denying culture
   —   fear
   —   isolation
   —   anger
   —   searching for cure/treatment/meaning
   —   hopelessness
   —   complicated grief
   —   distress

♦   Positive:
   —   acceptance
   —   relief
   —   hope
   —   saying goodbye
   —   grief and loss (normal)

Outcome 3

Ethical dilemmas related to the last days of life can include:

♦   Cardio Pulmonary Resuscitation (CPR)
♦   Do Not Resuscitate (DNR)
♦   capacity to make choices/decisions
♦   withholding/withdrawing treatment
♦   withholding/withdrawing food and fluids
♦   truth telling/honesty
♦   human rights

Important dilemmas that involve decision making and the need for more information that is pertinent to end of life choices:

♦   place of care
♦   continuing treatment
♦   resuscitation
♦   advocacy/living wills/advanced directive
♦   Anticipatory Care Planning (ACP)
♦   symptom management/control
♦   family collusion withholding information

National Unit Support Notes (cont)

Unit title: Care in the Last Days of Life (SCQF level 6)

The role of an advocate and a proxy decision maker including the reason for these roles:

♦   definition of an advocate
♦   definition of a proxy decision maker
♦   definition of a power of attorney/welfare of attorney
♦   adult with Incapacity (Scotland) Act 2000
♦   safeguarding a vulnerable adult

Outcome 4

Caring for people in the last days and hours of life — National Guidance
http://www.gov.scot/Publications/2014/12/6639

Principles for end of life care

Principle 1: Informative, timely and sensitive communication is an essential component of each individual person's care.

Principle 2: Significant decisions about a person's care, including diagnosing dying, are made on the basis of multidisciplinary discussion.

Principle 3: Each individual person's physical, psychological, social and spiritual needs are recognised and addressed as far as is possible.

Principle 4: Consideration is given to the wellbeing of relatives or carers attending the person.

Examples of local guidelines that contribute to improving care at the end of life may include:

♦   symptom management
♦   confirmation of death
♦   resuscitation guideline
♦   care in the last days of life
♦   nutrition and fluids at end of life
♦   spiritual care
♦   bereavement and support

Examples of a person's role in relation to organisational policy and procedures when a person dies:

♦   Confirmation of death — understand that person requires to be confirmed as dead according to local guidelines and procedures.
♦   Care after a death — care of the body, contacting transport to remove the body to mortuary or funeral home.
♦   Certification of death — know who does this and how to contact them.
♦   Registering a death — understand the legal requirement and documents needed to register a death.
♦   Awareness of cultural differences and practice to be adhered before and after death and know how to contact the professional person to lead this.

National Unit Support Notes (cont)

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Practical issues that surround death:

♦ funeral arrangements
♦ funeral poverty
♦ talking about death and coming to terms with new circumstances
♦ change in finances — financial review/assessment
♦ loneliness
♦ support groups for bereavement — specific to types of death, ie suicide/children
♦ returning to work.

Sources of support available for friends and family in the local area.

Online such as Dying Matters https://www.dyingmatters.org/
Support around Death http://www.sad.scot.nhs.uk/
Good Life Good Death Good Grief https://www.goodlifedeathgrief.org.uk/

Locally in communities there will be lots of groups that people can join to help counteract the loneliness they may feel following bereavement. In Scotland, there is a campaign to end loneliness and social isolation https://www.campaigntoendloneliness.org/press-release/action-group-on-loneliness-isolation-in-scotland-agil-welcomes-scotlands-first-loneliness-strategy/

As a result many health and social care partnerships are working more closely with organisations in local communities.

Guidance on approaches to delivery of this unit

Teachers/lecturers should be mindful of the sensitive and emotive nature of palliative care and how it may affect learners, especially those who have had a past bereavement or involvement with palliative care services. Relevant and appropriate support should be sought if required.

Palliative care is for people of all ages and delivered in all areas of health and social care. It is important that the teacher/lecturer directs learners to relevant statutory, non-statutory and third sector organisations to ensure learning is focused and comprehensive.

The use of the internet and appropriate reading materials should be encouraged to offer current thinking in relation to palliative and end of life care.

In delivering this unit, there should be a balance between teacher/lecturer led presentation and learner centred learning. Some learning and teaching activities may be carried out on a group basis and, where this applies, learners could also receive feedback from their peers.

Teachers/lecturers should, where possible, provide opportunities to personalise learning and enable learners to have choices in approaches to learning and teaching.

National Unit Support Notes (cont)

Unit title: Care in the Last Days of Life (SCQF level 6)

Teachers and lecturers should also create opportunities for, and use, inclusive approaches to learning and teaching. This can be achieved by encouraging the use of a variety of learning and teaching strategies which suit the needs of all learners, for example:

♦ group exercises
♦ group discussion
♦ use of case studies
♦ individual and/or group research
♦ use of videos
♦ lectures
♦ use of ICT such as web based material
♦ external speakers from specialist teams

Learners should be introduced to the government frameworks and policy guidance including palliative and end of life care; enriching and improving experiences.
https://learn.nes.nhs.scot/2450/palliative-and-end-of-life-care-enriching-and-improving-experience

The framework promotes a consistent, inclusive and flexible approach to learning and development on palliative and end of life care for the health and social service workforce. It is aspirational and values workers' previous learning, and existing knowledge and skills. It acknowledges the place of informal and formal learning in supporting the workforce to develop knowledge and skills, and recognises sector and discipline-specific standards and frameworks, such as National Occupational Standards and the NHS Knowledge and Skills Framework.

The framework's flexibility enables it to be used in different ways to support learning and development at individual, service-provider and organisational levels.

Guidance on approaches to assessment of this unit

Evidence can be generated using different types of assessment. The following are suggestions only. There may be other methods that would be more suitable to learners.

The Assessment Support Pack for this unit provides sample assessment material. Centres wishing to develop their own assessments should refer to the Assessment Support Pack to ensure a comparable standard.

Centres are reminded that prior verification of centre-devised assessments would help to ensure that the national standard is being met. Where learners experience a range of assessment methods, this helps them to develop different skills that should be transferable to work or further and higher education.

An integrated approach to assessment is recommended.

Outcomes 1 to 4 could be integrated and assessed by an individual or small group development of an information booklet. This booklet can then be given to families and carers to support conversations about the care received by their family member/friend, and the professionals involved.

National Unit Support Notes (cont)

Unit title: Care in the Last Days of Life (SCQF level 6)

Opportunities for e-assessment

E-assessment may be appropriate for some assessments in this unit. By e-assessment we mean assessment which is supported by Information and Communication Technology (ICT), such as e-testing or the use of e-portfolios or social software. Centres which wish to use e-assessment must ensure that the national standard is applied to all learner evidence and that conditions of assessment as specified in the evidence requirements are met, regardless of the mode of gathering evidence. The most up-to-date guidance on the use of e-assessment to support SQA's qualifications is available at **www.sqa.org.uk/e-assessment**.

Opportunities for developing Core and other essential skills

There are opportunities to develop the following Core Skills:

♦ *Communication* at SCQF level 6
♦ *Information and Communication Technology (ICT)* at SCQF level 6
♦ *Numeracy* at SCQF level 6
♦ *Problem Solving* at SCQF level 6
♦ *Working with Others* at SCQF level 6

Communication — may be evidenced via the learner's work with individuals and groups as well as within written assessments.

Information and Communication Technology (ICT) — may be evidenced by the learner's ability to accessing, processing, and presenting information.

Numeracy — may be evidenced by the learner's ability to use graphical information to support research, presentations as well as within written assessments.

Problem Solving — may be evidenced through facilitated group discussion about the most appropriate course of action for care delivery.

Working with Others — may be evidenced in the learner's ability to interact, communicate and negotiate with those with whom they come into contact, and to work collaboratively with other professionals and individuals, recognition of professional boundaries and professional conduct in practice.

History of changes to unit

Version	Description of change	Date

General information for learners

Unit title: Care in the Last Days of Life (SCQF level 6)

This section will help you decide whether this is the unit for you by explaining what the unit is about, what you should know or be able to do before you start, what you will need to do during the unit and opportunities for further learning and employment.

This unit is designed to enable you to develop your knowledge and understanding of end of life care. The unit will examine the dying process and common conditions experienced at the end of life. In addition, the importance of communication in the last days of life and the promotion of choices and preferences will also be explored. This includes responding to the bereavement needs of the individual's family or significant others. Current ethical dilemmas surrounding decisions made in the last days of life with be examined together with the principles, legislation and guidelines that direct end of life care.

Palliative care aims to prevent and alleviate suffering associated with life limiting and life shortening illnesses. It is particularly beneficial as the individual experiences symptoms associated with advanced disease and as they approach the end of their life. Death is universal but is unique to every person. Therefore, the learner will develop a growing recognition of the dying process and common symptoms. The importance of good communication is emphasised throughout and it will be necessary to investigate the underpinning ethical dilemmas and decisions often raised by families. This is something that people working in caring services must acknowledge and respect and is often intertwined in legislation, local policies and guidelines.

This unit is a mandatory unit in the National Progression Award (NPA) Palliative and End of Life Care at SCQF level 6. The unit can also be studied on a stand-alone basis. The unit is suitable for care students and or individuals employed in the care sector.

This unit consists of four outcomes. On successful completion of these, you will be able to:

1   Describe the dying process including common symptoms experienced in the last days of life.
2   Explain the importance of effective communication in the promotion of choices and preferences of the individual, family and carers in the last days of life.
3   Explain ethical dilemmas that relate to decision making in the last days of life.
4   Describe how principles, legislation, policy and guidelines direct care when a person dies.

Outcomes 1 to 4 could be integrated and you will be assessed by an individual or small group development of an information booklet. This booklet can then be given to families and carers to support conversations about the care received by their family member/friend, and the professionals involved.

You will be introduced to the government frameworks and policy guidance including palliative and end of life care; enriching and improving experiences.
https://learn.nes.nhs.scot/2450/palliative-and-end-of-life-care-enriching-and-improving-experience

General information for learners (cont)

Unit title: Care in the Last Days of Life (SCQF level 6)

The framework promotes a consistent, inclusive and flexible approach to learning and development on palliative and end of life care for the health and social service workforce. It is aspirational and values workers' previous learning, and existing knowledge and skills. It acknowledges the place of informal and formal learning in supporting the workforce to develop knowledge and skills, and recognises sector and discipline-specific standards and frameworks, such as National Occupational Standards and the NHS Knowledge and Skills Framework.

The framework's flexibility enables it to be used in different ways to support learning and development at individual, service-provider and organisational levels.

You will have the opportunity to develop the Core Skills of:

Communication at SCQF level 6 — may be evidenced by your work with individuals and groups as well as within written assessments.

Information and Communication Technology (ICT) — may be evidenced by accessing, processing, and presenting information.

Numeracy — may be evidenced by the use of graphical information to support research, presentations as well as within written assessments.

Problem Solving at SCQF level 6 — may be evidenced through facilitated group discussion about the most appropriate course of action for care delivery.

Working with Others at SCQF level 6 — may be evidenced by your ability to interact, communicate and negotiate with those with whom you come into contact, and to work collaboratively with other professionals and individuals, recognition of professional boundaries and professional conduct in practice.

The unit will facilitate the development of citizenship and includes; concern for others; being aware of rights and responsibilities; being aware of the democratic society; being outward-looking towards society; being able to recognise one's personal role in this context, and of acting responsibly. You will develop employability skills including the development of care specific knowledge and also an understanding of employment skills such as appropriate attitudes and behaviours.