SOS Kilkenny clg

End of Life Care Policy

Developed By:	Authorised By:	Date:
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Change to Document	***Date***	***Reason for Change***
Whole Document	May 2018	Management Structural Changes

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1. Policy Purpose

1.1. This document sets out the Policy and Procedures of SOS Kilkenny clg with regard to end of life care for our service users.

2. Introduction

2.1. SOS Kilkenny clg is committed to facilitating service users and their family members express their needs and wishes throughout the continuum of the end of life phase.

2.2. SOS Kilkenny clg is committed to addressing the physical, emotional, spiritual and social needs of service users at the end of life.

2.3. SOS Kilkenny clg is committed to providing an environment that is supportive of service users, families and staff.

2.4. SOS Kilkenny clg is committed to promoting respect and dignity for the dying service user.

3. Policy Aim

3.1. This document aims to ensure that service users receive a person-centered approach to end of life care.

3.2. The document aims to clarify for staff, service users and their families / representatives, the organisation’s approach to end of life care.

3.3. ensuring that all service users with palliative and end-of-life care needs are identified and assessed

3.4. care plans are in place to meet the end-of-life needs of service users and their families

3.5. the service user’s needs are communicated and coordinated clearly within the centre and other healthcare settings

3.6. healthcare professionals and non-clinical staff possess an appropriate level of knowledge,

   3.6.1. skills, competence and confidence to care for service users approaching end of life.

4. Policy Scope

4.1. This document applies to:

   4.1.1. All service users availing of services provided by SOS Kilkenny clg.

   4.1.2. All staff working in SOS Kilkenny clg.

5. Roles & Responsibilities

5.1. The Chief Executive Officer:

5.1.1. The Chief Executive Officer who has overall responsibility for ensuring that procedures and processes are in place to enable adherence to this Policy.

5.1.2. That where additional resources are required, the CEO must make the required resources available to the service manager.

5.1.3. That arrangements for the identification, recording and investigation of, and learning from serious incidents such as a death involving service users are in place and followed through.

5.1.4. The CEO will ensure there is provision of adequate training and awareness of this policy.

5.1.5. The CEO will inform and engage with all regulatory obligations of the organisation following the death of a service user.

5.2. Management:

5.2.1. All Managers are responsible for the following in relation to this policy.

5.2.1.1. That they and all their staff within their responsibility are familiar with the contents of the End of Life Care Policy and are working to adhere to this policy.

5.2.1.2. It is important that end-of-life care is coordinated by the relevant manager.

5.2.1.3. To ensure good communication systems and clear documentation are maintained to ensure consistent delivery of quality end-of-life care.

5.2.1.4. To ensure that all End of Life Care Plans are reviewed annually or sooner if circumstances change.

5.2.1.5. To ensure meetings between medical and nursing staff and the input of any external professionals to inform and be reflected in the care plan.

5.2.1.6. Ensure that all policies, procedures, protocols and guidelines are implemented as appropriate.

5.2.1.7. Ensure that all deaths are reported, effectively managed, including action, review, monitoring, learning and escalation.

5.2.1.8. It is the responsibility of all managers to ensure that all staff are familiar with this policy.

5.3. Staff:

5.3.1. All front line staff are responsible in relation to End of Life Care.

5.3.2. It is the responsibility of all employees to be familiar with this policy.

5.3.3. To ensure that all End of Life Care Plans are reviewed annually or sooner if circumstances change.

5.3.4. To communicate at all times in a sensitive and professional manner with the service user and families and to encourage family members to be involved where appropriate.

5.3.5. To ensure meetings between medical and nursing staff and the input of any external professionals to inform and be reflected in the care plan.

5.3.6. To ensure An atmosphere of peace and calm, privacy and dignity is maintained for service user at end of life.

5.3.7. To contact the relevant manager or the Emergency on Call service as soon as possible following the death of a service user.

5.3.8. Contact the relevant GP or emergency services as per the End of Life Care plan or in the case of a sudden death the emergency services.

5.3.9. Complete an incident form within 24 hours of the death occurring.

5.3.10. Report any incidents not in compliance with this policy.

6. Definitions

6.1. **End of Life Care:** There are a variety of definitions of “end of life” and “end of life care”, but no one broadly agreed definition. Irish Hospice Foundation use the following definition (hospice foundation 2016):

6.1.1. End of life care / Care at end of life – We use these terms to refer to all aspects of the care relating to dying, death and bereavement which is provided towards the end of life. In this context, ‘end of life’ can be from the point of receiving a life-limiting diagnosis through the months before death, up to and including the final hours – a continuum rather than a point in time. We use ‘end-of-life care’ to refer to the care of people with advanced life-limiting conditions, for whom death within 1-2 years is likely, as well as those in the terminal phase of illness. It also encompasses care of the bodily remains of the deceased person.

6.1.2. End of Life Phase: “Applies to people with a variety of conditions and involves a longer time period that the days or weeks immediately before death”. (National Council for Ageing and Older People, NCAOP, 2008)

6.2. **Palliative Care:** The World Health Organisation (2015) defines palliative care as:

6.2.1. “An approach that improves the quality of life of service users (adults and children) and their families who are facing problems associated with life-threatening illness, it prevents and relieves suffering through the early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”.

6.2.2. **Palliative Care:**

- 6.2.2.1. Provides relief from pain and other distressing symptoms
- 6.2.2.2. Affirms life and regards dying as a normal process
- 6.2.2.3. Intends neither to hasten or postpone death
- 6.2.2.4. Integrates the psychological and spiritual aspects of service user care.
- 6.2.2.5. Offers a support system to help service users live as actively as possible until death.
- 6.2.2.6. Offers a support system to help the family cope during the service user's illness and in their own bereavement
- 6.2.2.7. Uses a team approach to address the needs of service users and their families, including bereavement counseling, if indicated
- 6.2.2.8. Palliative care improves the quality of life of service users and their families who are facing problems associated with life-threatening illness, whether physical, psychosocial or spiritual. (WHO 2015)

6.3. **Terminal Care:**

6.3.1. The service user is in the final days or weeks of life. Symptoms
6.3.1.1.1. that are considered to indicate a terminal phase of life include:
6.3.2. Requiring frequent intervention
6.3.3. Being bed-bound
6.3.4. Loss of appetite
6.3.5. Profound weakness
6.3.6. Trouble swallowing
6.3.7. Dry mouth
6.3.8. Weight loss
6.3.9. Becoming semi-conscious, with lapses of unconsciousness.
6.3.10. Experiencing day-to-day deterioration that is not reversible. (Adapted from NCAOP, 2008; Missouri End of Life Coalition, 2003; Australian Government, Guidelines for a Palliative Approach in service user Aged Care, 2006).

7. Guiding principles for End of Life Care:

7.1.1. Assessment of end of life needs and provision of end of life care should be based on the service user's current condition and wishes. Where the service user is unable to inform you of their wishes, it should be based on their needs and should take into account the views and considerations of their family / representatives.

7.1.2. Service users can move in and out of different stages of end of life and may require different levels of care / support throughout their journey in the service.

7.1.3. Good communication between the service users, service user's family/representative, and all staff is an important requisite to ensure that staff are aware of the service user's specific needs related to his/her end of life stage.

7.1.4. Decision-making around end of life care should comply with the Assisted Decision Making (Capacity) Act 2015 (Statute book 2015). The Assisted Decision – Making (Capacity) Act legislates for when a person whose capacity to make a decision is in question can appoint a person to assist, co- decide or has somebody appointed to represent them for the purpose of making a decision.

7.1.5. All aspects of assessment and care planning for end of life needs should be underpinned by an approach that ensures respect for privacy and dignity for the service user and their representative(s).

7.1.6. Any expressed wishes made by the service user regarding future end of life care should be documented in the service user's care plan (e.g. a service user may express the wish not to be transferred to hospital in the event of their condition deteriorating, However, certain conditions may lead to service user requiring hospitalisation). This however must be done in consultation with the service user's General Practitioner and allied health professionals with consideration given to the level of medical expertise available within the service user's home.

7.1.7. If a service user is admitted to hospital, they are under the primary care of the consultant but will continue to be supported by SOS. (See Appendix 1 – End of life care plan and Abbey Pain Scale).

7.1.8. End of life care should focus on quality of living as well as quality of dying.

7.1.9. End of life care should include addressing any loss or grief the service user may be experiencing.

7.1.10. The needs of the service user's family/representative(s) for support should be included in end of life care planning.

7.1.11. All staff providing end of life care to service users should have the requisite skills and competencies commensurate with their grades/disciplines.

7.1.12. Should a family wish to have a service user in their family home to care for them during their end of life, SOS will support them to do so in so far as is reasonably practicable.

8. Assessment for End of Life Care Needs:

8.1. Identification of end of life care needs will depend on what stage of end of life the service user is at. However, identification of needs should commence with assessment of all care domains as part of the initial admission assessments, routine reassessments and reassessments carried out where there is a significant change in the service user's care and/or condition. This approach should ensure that a service user's changing condition or progression through their end of life and associated needs will be identified:

8.1.1. Specific end of life care needs will depend on the care level the service user is at, but the following areas should be considered:
8.1.2. Response to loss of function
8.1.3. Response to loss of previous lifestyle
8.1.4. Needs related to changes in mood (e.g. loneliness, depression and anxiety)
8.1.5. Pain
8.1.6. Nutrition and hydration
8.1.7. Incontinence
8.1.8. Alterations in cognition
8.1.9. Fatigue
8.1.10. Physical distress
8.1.11. Emotional/psychological distress
8.1.12. Expressed anxiety regarding death

8.2. **Assessment of palliative care needs.** Unlike other services such as dedicated cancer services, the timing of introducing palliative care is more complex. It is recommended that the timing of introducing palliative care should be determined by the service user's needs rather than prognosis and estimated survival time.

8.3. The following questions are recommended to trigger healthcare staff to consider the need to move the service user to an advanced level of care involving a palliative care approach:

8.3.1. Does the service user and/or the family choose treatment goals directed towards the relief of symptoms, rather than curing the underlying disease?

8.3.2. Has there been a new diagnosis? Significant diagnoses might include cancer, dementia, multiple sclerosis, motor neuron disease, stroke or heart failure.

8.3.3. Has the service user had a recent decline in functional status? (e.g. bathing, dressing, mobility, verbal communication, energy level and mood)

8.4. Decisions regarding implementation of advanced or palliative care should be collaborative between the staff team and other relevant healthcare professionals involved in the service user's care (e.g. General Practitioner); the service user as far as he/she is able and the service user's representative, as appropriate.

8.5. Assessment for palliative care needs should be based on a person- centered approach, this to include an assessment of all domains of the person's life, with an additional focus on symptom assessment, psychological and spiritual needs.

8.6. Common areas of symptom distress requiring assessment include nutritional problems, bowel problems, dyspnoea, fatigue, insomnia, pain, nausea and dysphasia.

8.7. Assessment of a service user in the palliative care stage should also focus on psychological needs and the presence of psychological distress. The most common psychological problems for service users requiring a palliative approach are depression, confusion and anxiety. The Edmonton Symptom Assessment Scale (ESAS) (See Appendix 2) may be useful to monitor the severity of psychological distress where psychological symptoms related to this stage are marked.

8.8. Referral to Community Palliative Care Services and/or Home Care Team is done in consultation with the individuals General Practitioner and Family or advocate.

8.9. The following indicators have been recommended as triggers for referral of a person to specialist palliative care:

8.9.1. Increase in intensity of symptoms, e.g.
  8.9.1.1. pain,
  8.9.1.2. dyspnoea,
  8.9.1.3. terminal agitation, that cannot be managed at local level.

8.10. Assessment of spiritual needs. Assessment of spiritual needs is an important aspect of palliative care and an ongoing process. Understanding the service user's current or desired practices, attitudes, experiences and beliefs assists in meeting their spiritual needs.

8.11. Assessment for palliative care should include identifying the needs of family/significant others for support and information.

8.12. All assessments should be documented in the relevant section of the service user's records.

9. Care planning for End of Life Care Needs

9.1 Where a service user has assessed needs with regard to end of life care, a care plan should be put in place to meet these needs and should identify how often the plan is reviewed with particular reference to the changing needs of the service user during end of life care.

9.2 The care plan should be person centered for each service user requiring advanced/palliative care and should include measures to support the service user and his/her representatives with bereavement.

9.3 The care plan should be based on the service user's current condition and wishes. Where the service user is unable to inform you of their wishes, it should be based on their assessed needs and should take into account the views and considerations of their family / advocate.

9.4 The manager ensures the relevant staff will liaise with relevant family members where appropriate and healthcare professionals involved in the service user's care (e.g. the General Practitioner) when developing the care plan.

9.5 Care planning for end of life should include the following areas:

- 9.5.1 Fundamental care needs as indicated by the screening and comprehensive assessments and reassessments.
- 9.5.2 Management of symptoms.
- 9.5.3 Psychological care needs.
- 9.5.4 Spiritual care needs.
- 9.5.5 Promotion of health and wellbeing.
- 9.5.6 Promotion of quality of life.
- 9.5.7 The service user as far as he/she is able should be at the centre of decision-making. Decision-making should be underpinned by the principles of autonomy of the service user's right to make decisions about his/her care.
- 9.5.8 The care plan should be documented and regularly reviewed with the service user. It may include:
  - 9.5.8.1 The service user's wishes and choices regarding end-of-life care, which should be implemented **as far as possible.**
  - 9.5.8.2 The service users values, concerns, fears and personal goals for care the service users understanding of their illness and prognosis.

9.5.8.3 The service user's physical, social, emotional, spiritual and cultural needs the service users preferred place of care and death including the option of a single room or returning home – depending on services available to support this.

9.5.8.4 What do to if there is a change in the service user condition which should include:

9.5.8.4.1 when a service user should or should not be transferred to an acute hospital

9.5.8.4.2 interventions which may be considered or undertaken in an emergency, such as antibiotics, if an service user has an accident or sustains a fracture and cardiopulmonary resuscitation (CPR) any other matter which the service user considers important.

9.6 The service user's and their representative's wishes/choices relating to treatment and care should be discussed and documented in the care plan and reviewed during each review of the care plan.

9.7 Consent and information provision:

9.7.1 Information given to service users to enable them make decisions and give consent must be given in the right manner at the right time in the appropriate place by the appropriate person.

9.7.2 The information should be accurate, clear and simple in appropriate language that the service user can understand, to exercise their choice and autonomy and allow them to be informed about any decisions they may have to make regarding the service, their treatment, activities, health and safety.

9.7.3 The information given must be appropriate to the service user's wellbeing, best interest and mental and cognitive ability.

9.7.4 There is a core need to access and review the right information at the right time to make the best decisions.

9.7.5 Informed consent is an ongoing process and decision-making should reflect the service user's current condition.

9.7.6 Assessment of Capacity – every service user must be presumed to have mental capacity to consent or refuse treatment unless proved otherwise.

9.7.7 Where a service user does not have the capacity to make decisions about care or give consent, decisions regarding care needs during end of life care should be of a collaborative nature and made in the best interest of the service user in line with the Assisted Decision Making (Capacity) Act 2015.

9.7.8 The service user's representative/family members and/or advocate should be involved in the decision-making in this instance. The views and observations of the representative/family members/advocate should be sought in order to aid decision-making.

9.7.9 The house/centre manager should liaise with the house / centre team to arrange meetings with the service user (if he or she is able); his/her representative or family members/advocate to discuss any issues related to end of life decisions. The house /centre team should involve the key worker / social worker the service user's GP and any palliative care specialists involved in the service user's care.

9.7.10 Information and views regarding what the service user would want, including any previous discussions or expressed wishes should be ascertained.

9.7.11 Discussions should take cognisance of the risks and benefits of treatment/interventions to the service user.

9.7.12 Discussions and their outcomes should be documented in the service user's record

10 Care of The Dying (Terminal Phase)

10.1 The terminal phase refers to the last 48-72 hours of life.

10.1.1 The terminal phase is usually characterised by common signs that indicate that the service user is deteriorating. These include severe weakness, decreased oral intake, difficulty taking medication and drowsiness. Additionally, the service user may appear disoriented and have difficulty in concentration.

10.1.2 Management of the terminal phase should be underpinned by the following principles:
10.1.3 Every effort made to optimise symptom management
10.1.4 Dignity, privacy and respect should be provided and maintained
10.1.5 The individual needs and preferences of the service user are ascertained and respected as far as is possible.
10.1.6 Communication is optimised for all people involved (service user, family, staff)

10.1.7 The service user and family feel unhurried and valued
10.1.8 Staff are enabled and supported to deliver the highest possible standard of care

10.2 There are five symptoms that are common in the dying phase, although not all service users will experience these. They are:
102.1.Pain
102.2Nausea and Vomiting
102.3Agitation and Distress
102.4Respiratory tract secretions
102.5Dyspnoea

10.3Service users entering the dying phase should be reviewed by the staff team in collaboration with the service user’s GP, family members and other healthcare professionals involved in the service user’s care.

10.4The service user’s representative should be informed once it is confirmed that the service user is dying.

10.5The staff in charge of the house at the time should check the service user’s records to ascertain the name and contact details of the person(s) to be informed, e.g. family members / representative(s), priest etc.

10.6An assessment of needs should be carried out to include:
10.6.1 Presence and severity of physical symptoms
10.6.2 Level of orientation
10.6.3 Presence of distress, such as fear and anxiety
10.6.4 Review of non-essential medications and interventions
10.6.5 Physical needs such as bowel, bladder, skin integrity, personal hygiene, eye care and pressure area care
10.6.6 Comfort needs
10.6.7 Psychological needs
10.6.8 Spiritual needs
10.6.9 Needs of family/carer’s for bereavement support

10.7The service user’s care plan should be updated to reflect the needs, known wishes and preferences of the service user and family members.

10.8The service user’s care and condition should be monitored frequently to reflect changes in care and/or condition, but no less frequently than hourly. Changes to care and/or condition should be recorded in the person’s notes.

10.9 A record of medications administered should be recorded as well as the effectiveness of same.

10.10 The person in charge/manager should ensure that a staff member is available to the family at all times when a service user is dying.

10.11 Communication Needs:

10.11.1 It is important that the service user is given the opportunity to discuss fears and ask questions.

10.11.2 Where a staff member feels he/she is unable to answer the question, she should liaise with the person in charge/manager or the service user's GP as appropriate.

10.11.3 As part of the care, time should be allocated for communication with the service user and his/her family members, to listen and discuss fears and concerns.

11 Additional requirements for service users with challenges in verbalising their needs and wishes:

11.1 Knowledge of the service user is an essential pre-requisite for meeting his/her needs.

11.2 Service users should be monitored for signs of distress/agitation that may indicate pain or other discomfort. Behavior monitoring charts and observation charts should be considered as possible aids to monitoring signs of increasing distress. (See Appendix 1 End of life care plan and Abbey Pain Scale).

11.3 The care plan should include measures for monitoring verbal and non- verbal clues that may indicate distress as well as methods of communication, including use of non-verbal methods.

11.4 Family members should be involved in care planning and can be a valuable resource for understanding non-verbal cues and behaviors.

12 Procedures for managing the death of a service user.

12.1 Inform all other service users as soon as possible. All staff present in the service should then be informed.

12.2 Friends, advocates and other staff should be told as soon as is reasonably possible.

12.3 Comfort family and enquire as to their wishes regarding clothes for laying out, funeral arrangements etc. (if not already planned).

12.4 Contact the nominated funeral directors for the removal of the deceased to the funeral home/family home as per End of Life Care Plan.

12.5 If a person has prepared instructions regarding their spiritual preferences, these should be respected.

12.6 Update service users and staff regarding funeral arrangements. Assist them with attending the funeral if required.

12.7 Encourage and acknowledge sharing/discussion of response to the news. People may have stories/emotions about the deceased that they wish to share.

12.8 Staff may feel sad and may need support in expressing their grief and sadness so as to enable them to comfort other service users at this time.

12.9 Remind staff of the Employee Assistance Programme counseling services and offer de-briefing service if deemed appropriate.

12.10 Arrange months mind/service if requested to do so by family.

13 Verification of Death

13.1 The following procedure should be followed in the following situations:

13.1.1 The expected of a death of a service user
13.1.2 The sudden death of a service user
13.1.3 The discovery of a sudden death of a service user

12.2 Contact the doctor / doctor on call and inform them.

13.1.4 Contact the service user’s family if they are not already present.
13.1.5 Contact the relevant manager or the on call manager if the manager is not available.
13.1.6 Follow any specific instructions in the End of Life Care Plan.
13.1.7 Do not move the service user until the Doctor has verified death and has instructed you on any necessary action.
13.1.8 The deceased may need to be transferred to a designated hospital for Post Mortem in some circumstances A post-mortem will be carried out as soon as possible, usually within 2 to 3 working days of a person's death. In some cases, it may be possible for it to take place within 24 hours.

14 Notifying Relevant Authorities:

14.1 SOS Internal Notification

14.1.1 Following the death of a service user an incident form must be completed and submitted to the relevant manager within 24 hours of the death.

14.2The County Coroner

14.2.1 The protocol in S.O.S. is that a G.P. is called when a death occurs in. S.O.S. Kilkenny clg (including service users receiving care in their own home.

13.1.2. The GP will notify the coroner if necessary in consultation with t he person's family and relevant S.O.S. Manager or Team leader.

13.1.3 Deaths reportable to the Coroner:

13.1.3.1 When a death is due to natural causes, and the attending doctor can certify the cause of death, a post-mortem examination, also called an autopsy, is not needed.

13.1.3.2 However, if there is any aspect of the service user's illness needing clarification or confirmation, the treating doctor or the next-of-kin may think a post-mortem is desirable.

13.1.3.3 When the cause of death is unknown, and in certain other circumstances, the Coroner is obliged by law to order a post-mortem.

13.1.3.4 If the deceased has not been seen and treated by a registered medical practitioner within 28 days before death

13.2. The Health Information & Quality Authority [HIQA]

13.2.1 An NFO1D form is required to be submitted to HIQA within three working days following an unexpected death of any service user, including the death of any service user following transfer to hospital from the designated service.

13.2.2 This form will be completed by the relevant manager or senior manager.

15 Registering the death

15.1If the GP is satisfied with the cause of death a death certificate may be issued as follows: The GP who attended the deceased must complete and sign Part 1 of the Death Notification Form, stating to the best of his or her knowledge the cause of death.

15.2The GP must give the Death Notification Form to a member of staff or next of kin of the deceased.

15.3The Death Notification Form stating the cause of death must be presented to any Registrar for registration. This registration is free.

15.4Deaths must be registered as soon as possible after the death and no later than three months. Log onto www.birthdeathsmarriages.ie for local details.

15.5In Kilkenny deaths are registered in The Community Care Offices in James Green.

16 External Notifications

16.1 The C.E.O. will ensure that the H.S.E. Disability Manager and/or H.S.E. Case Manager/Liaison Officer and H.I.Q.A are informed.

16.2 The C.E.O. will ensure that the Ward of Court Office is informed if the service user is a Ward of Court.

16.3 The C.E.O. will ensure that any suspicions or concerns regarding the death must be notified to the Gardai and instructions followed.

17 Service user's personal belongings

17.1 A client property record is maintained of all personally owned items (e.g. furniture, jewelry etc.) kept in the service user's file/apartment/bedroom.

17.2 Staff will support family with removal of personal items from S.O.S. Kilkenny clg.

17.2.1 Any cash held on behalf of the service user or discovered in their accommodation should be counted, noted, witnessed and sent to the S.O.S. Finance Department who will return to their next of kin.

17.2.2 Any financial possessions including bank or credit union book or ATM cards are sent to the S.O.S. Finance Department and returned to the next of kin and documented.

18 Management of funds held by S.O.S. Kilkenny clg (in a bank account) on behalf of the deceased service user:

18.1 The Manager or Team Leader should enquire if the service user had made a Will – if so; the funds held by S.O.S. Kilkenny clg are covered by the Grant of Probate.

18.2 If the service user has not made a Will, S.O.S. Kilkenny clg requires a Grant of Administration to be furnished, to direct the forwarding of any funds held by S.O.S. Kilkenny clg on behalf of the person.

18.3 If the family does not wish to get a Grant of Administration, their solicitor can draw up a letter to S.O.S. Kilkenny clg, signed by the family members, with indemnity to S.O.S. Kilkenny clg to any future claims on the funds. This letter should instruct S.O.S. Kilkenny clg as to whom the funds should be paid.

19 This Policy should be read in conjunction with the following policies:

19.1 The SOS Kilkenny clg Data Protection Policy

19.2 The SOS Kilkenny clg Data Breach Policy

End of Life Care Plan.

Appendix 1 End of Life Care Plan and Abbey Pain Scale

Profile of Service user

My name is: ____________________________ My Date of Birth is: _____________

My Address is:

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My current medical condition is:

My multi-disciplinary team:

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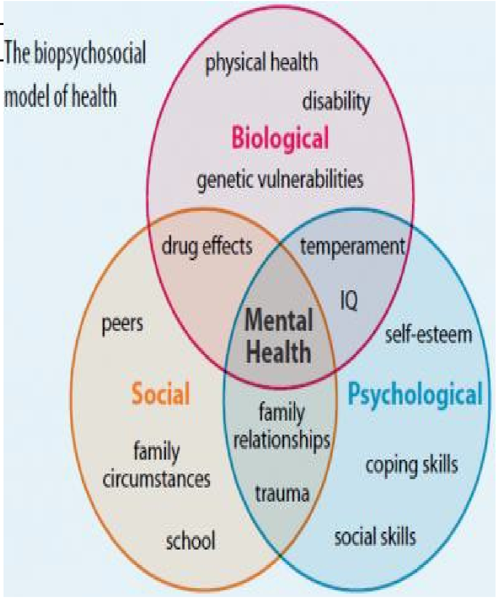


My care has been described as End of Life Care this term is used to refer to all aspects of the care provided to me with my life-limiting illness, from the time of my diagnosis through the last months of life, up to and including the final hours.

We consider 'end of life' to be a continuum rather than a point of time (Irish Hospice Foundation).

This document will provide you with the information that you require in order to provide me with the best possible End of Life Care that I can receive.

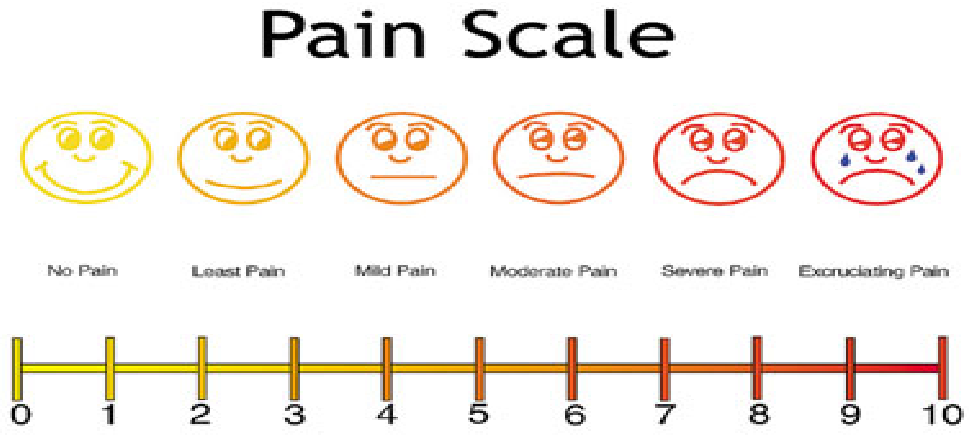
My needs are identified by staff using a bio-psycho-social model of care ensuring that I am provided with a holistic approach to my care.

This care plan will ensure that I maintain optimum health in all areas of my life and will assist you as my carer in providing me with a person centered approach.

I require supports with the following areas.

My Physical Wellbeing:

Pain:



When assessing my level of pain please use the abbey pain scale, you will find a copy of this in appendix 1 of my End of Life Care Plan. The Pain Scale is an instrument designed to assist in the assessment of pain in individuals like me who are unable to clearly articulate their needs. This particular pain scale will assist you if you are unsure of whether I am in pain or not, and if I am this pain scale will assist you in ascertaining my level of pain.

In the event that I do present as having pain please look at my pink PRN sheet in my Medication Kardex and you will see that I have been written up for the following pain relieving medications:

NB:

Please read the PRN protocol sheets around the administration of these medications before administering them, you will find the protocols in my kardex.

In the event that I present with any respiratory distress please look at my pink PRN sheet in my kardex and you will see that I have been written up for the following medications:

NB:

Please read the PRN protocol sheets protocol sheets around the administration of these medications before administering them, you will find the protocols in my kardex.

Eating and Drinking:

Please refer to my Speech and Language care plan to ensure that you follow the correct guidelines when attending to my nutritional requirements:

Fatigue:

Maintaining Skin Integrity:

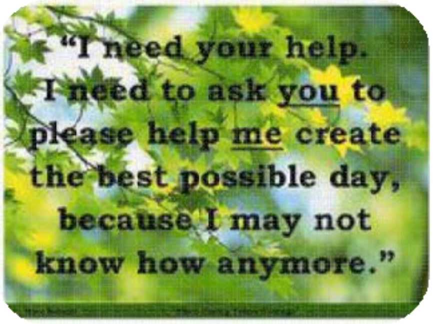
Social and Occupational Well-Being:

Social:

Occupational.:

My goals for the future for social and occupational wellbeing would be for my staff team to continue to provide me with the best possible care to ensure that all of my needs continue to be met.

Psychological Wellbeing:



Spiritual Well-Being:

When my Death becomes imminent:

When my death is imminent and the appropriate healthcare personnel have deemed any further treatment to be futile please ensure that the following wishes are adhered to:

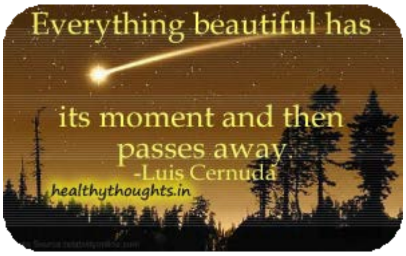
- Contact my family: ______________________
- Contact my priest: _______________________
- Ensure an atmosphere of peace and calmness.
- Ensure that you attend to my oral hygiene;
- Provide relief from distress this will facilitate a comfortable passing, and one that is remembered with peace and comfort by family and friends (An Bord Altranais 2009)

- Please be mindful of the decision regarding my resuscitation which is:

  ____

- This decision has been made with:

  ____



In the Event of my Passing

Caring for the remains of a deceased service user is one part of the overall continuum of care given to people at the End of Life and those close to them. Please ensure that you contact a GP and also my family. At all times my dignity and respect will be maintained.

My wish is:

____
____
____
____

I will be buried in:

____
____
____

Consult with the SOS End of Life Policy in relation to returning my personal possessions to my family.

Signed by:____
Service Users Name.

Signed By:____
Family Member / Next of Kin

Signed____________________________________
Keyworker/Person Completing EOL Care Plan

Signed____________________________________
Manager:

Signed____________________________________
Senior Manager

Signed_____________________________________
Service Users G.P.

Date EOL Care Plan Completed: _________________

Abbey Pain Scale Appendix 2

For measurement of pain in people with dementia or who cannot verbalise

How to use scale: While observing the resident, score questions 1 to 6

*Name of resident:*____

Name and designation of person completing the scale: ______________________________________

Date: __________________________________**Time:** ______________________________________

Latest pain relief given was:____**at**______________**hours**

Q1. **Vocalisation**

e.g. whimpering, groaning, crying

Absent 0 *Mild 1* *Moderate 2* *Severe 3*

Q1 ☐

Q2. **Facial Expression**

e.g. looking tense, frowning, grimacing, looking frightened

Absent 0 *Mild 1* *Moderate 2* *Severe 3*

Q2 ☐

Q3. **Change in body language**

e.g. fidgeting, rocking, guarding part of body, withdrawn

Absent 0 *Mild 1* *Moderate 2* *Severe 3*

Q3 ☐

Q4. **Behavioural changes**

e.g. increased confusion, refusing to eat, alteration in usual patterns

Absent 0 *Mild 1* *Moderate 2* *Severe 3*

Q4 ☐

Q5. **Physiological change**

e.g. temperature, pulse, or blood pressure outside of normal limits, perspiring, flushing or pallor

Absent 0 *Mild 1* *Moderate 2* *Severe 3*

Q5 ☐

Q6. **Physical changes**

e.g. skin tears, pressure areas, arthritis, contractures, previous injuries

Absent 0 *Mild 1* *Moderate 2* *Severe 3*

Q6 ☐

Add scores for 1 – 6 and record here ⇨ **Total Pain Score** ☐

Now Tick the box that matches the Total Pain Score ⇨

0 – 2 **No Pain**	**3 – 7** **Mild**	**8 – 13** **Moderate**	**14 +** **Severe**

Finally, tick the box which matches the type of pain ⇨

Chronic	**Acute**	**Acute On Chronic**

Use of the Abbey Pain Scale

The pain scale is to be used as part of an overall pain management plan. Some pain management strategies can be found at the web site below[1]

Objective

The pain scale is an instrument designed to assist in the assessment of pain in residents who are unable to clearly articulate their needs.

Ongoing assessment

The scale does not differentiate between distress and pain, therefore measuring the effectiveness of pain relieving interventions is essential.

Recent work by the Australian Pain Society[2] recommends that the Abbey pain scale be used as a movement based assessment. The staff recording the scale should, therefore, observe and record on the scale while the resident is being moved eg, during pressure area care, while showering etc.

Complete the scale immediately following the procedure and record the results in the resident's notes. Include the time of completion of the scale, the score, staff member's signature and action (if any) taken in response to results of the assessment, eg pain medication or other therapies.

A second evaluation should be conducted 1 hour after the intervention taken in response to the first assessment, to determine the effectiveness of any pain relieving intervention.

If, at this assessment, the score on the pain scale is the same, or worse, consider further intervention and act if appropriate. Complete the pain scale 4 hourly, meanwhile recording all pain relieving interventions undertaken, until the resident appears comfortable. If pain/distress persists, undertake a comprehensive assessment of all facets of resident's care and monitor closely over a 24 hour period, including any further interventions undertaken. If there is no improvement during that time, notify the medical practitioner of the pain scores and the action taken.

Pain Assessment in Advanced Dementia (PAINAD)[3] Appendix 3

Item	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne---Stokes respirations.	
Negative vocalisation	None	Occasional moan or groan. Low level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling or inexpressive	Sad. Frightened. Frowning	Facial grimacing.	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
A detailed description of each of these items is overleaf			**Total Score** *	

* Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0 = “no pain” to 10 = “severe pain”).

INSTRUCTIONS

- Observe the older person both at rest and during activity/with movement.
- For each of the items included in the PAINAD, select the score (0, 1, or 2) that reflects the current state of the person’s behavior. Add the score for each item to achieve a total score.
- Monitor changes in the total score over time and in response to treatment to determine changes in pain. Higher scores suggest greater pain severity.

Note: Behavior observation scores should be considered in conjunction with knowledge of existing painful conditions and surrogate report from an individual knowledgeable of the person and their pain behaviors.

Remember that some patients may not demonstrate obvious pain behaviors or cues.

BREATHING

1. Normal breathing is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. Occasional labored breathing is characterized by episodic bursts of harsh, difficult or wearing respirations.
3. Short period of hyperventilation is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. Noisy labored breathing is characterized by negative sounding respirations on inspiration or expiration. They may be loud, gurgling, or wheezing. They appear strenuous or wearing.
5. Long period of hyperventilation is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. Cheyne--- Stokes respirations are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

NEGATIVE VOCALISATION

1. None is characterized by speech or vocalization that has a neutral or pleasant quality.
2. Occasional moan or groan is characterized by mournful or murmuring sounds, wails or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. Low level speech with a negative or disapproving quality is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic or caustic tone.
4. Repeated troubled calling out is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. Loud moaning or groaning is characterized by mournful or murmuring sounds, wails or laments much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. Crying is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

FACIAL EXPRESSION

1. Smiling is characterized by upturned corners of the mouth, brightening of the eyes and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. Sad is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. Frightened is characterized by a look of fear, alarm or heightened anxiety. Eyes appear wide open.

4. Frown is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. Facial grimacing is characterized by a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut

BODY LANGUAGE

1. Relaxed is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. Tense is characterized by a strained, apprehensive or worried appearance. The jaw may be clenched (exclude any contractures).
3. Distressed pacing is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4. Fidgeting is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging or rubbing body parts can also be observed.
5. Rigid is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding (exclude any contractures).
6. Fists clenched is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7. Knees pulled up is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance (exclude any contractures).
8. Pulling or pushing away is characterized by resistance upon approach or to care. The person is trying to escape by yanking or wrenching him or herself free or shoving you away.
9. Striking out is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

CONSOLABILITY

1. No need to console is characterized by a sense of well being. The person appears content.
2. Distracted or reassured by voice or touch is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction with no indication that the person is at all distressed.
3. Unable to console, distract or reassure is characterized by the inability to sooth the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the

Appendix 2 Abbey Symptom Assessment System:

Numerical Scale
Regional Palliative Care Programme

Please circle the number that best describes:

No pain	0 1 2 3 4 5 6 7 8 9 10	Worst possible pain
Not tired	0 1 2 3 4 5 6 7 8 9 10	Worst possible tiredness
Not nauseated	0 1 2 3 4 5 6 7 8 9 10	Worst possible nausea
Not depressed	0 1 2 3 4 5 6 7 8 9 10	Worst possible depression
Not anxious	0 1 2 3 4 5 6 7 8 9 10	Worst possible anxiety
Not drowsy	0 1 2 3 4 5 6 7 8 9 10	Worst possible drowsiness
Best appetite	0 1 2 3 4 5 6 7 8 9 10	Worst possible appetite
Best Feeling of Well Being	0 1 2 3 4 5 6 7 8 9 10	Worst possible Feeling of Well Being
No shortness of Breath	0 1 2 3 4 5 6 7 8 9 10	Worst possible shortness Breath
Other problem	0 1 2 3 4 5 6 7 8 9 10	

Service user's Name: ______________________________

Date:___________________Time: _________________

Complete by (*check one*)
- ☐ Service user
- ☐ Caregiver
- ☐ Caregiver assisted

Guidelines for the Management of Symptoms

Symptom	Possible Causes	Assessment	Treatment Management
Pain	• Assessment of pain is a prerequisite to management. Management depends on assessment. • Fentanyl patches may be prescribed where stronger pain relief is needed. • Syringe drive may be considered to avoid the discomfort of frequent needles, where a number of medicines are being given or where the oral route is no longer appropriate. • Cancer pain is managed using the WHO 3 step analgesic ladder.		
Dyspnoea	Frequently associated with the end stages of various diseases such as cancer, cardiac failure, COPD and neurodegenerative disorders. May be exacerbated by anxiety.	Obvious causes related to known illness. Exacerbating factors such as anemia or anxiety. Additional factors such as pulmonary embolus, infection or left ventricular failure.	• Liaise with service user's GP or palliative care team re: specific interventions. • Reduce the need for exertion by providing equipment, drinks and call bell within reach. • Position to maximise breathing and lung expansion. • Identify and address any situational factors that trigger dyspnoea. • Discuss the meaning of symptoms and any service user's family concerns. • Discuss possible use of relaxation techniques and/or complementary therapies with GP and palliative care team. • Administer and monitor effects of pharmacological usage • E.g. opioids, oxygen. • Cooling techniques for pyrexia. • Breathing exercises.

Symptom	Possible Causes	Assessment	Treatment Management
Fatigue	May be related to reduced physical function/activities; pain; psychological problems; sleep disturbance and/or medication. Consistently associated with depression and/or anxiety.	Usually based on the service user's report of the symptom, although underreporting can be a problem and service users with I.D. may not be able to verbalise, so there is a need to observe for signs of fatigue.	Identify and address any contributing factors. If due to inactivity, exercise may be useful – liaise with GP and care team.
Anorexia/ Cachexia	Loss of appetite which is common in end stage disease. It may be intermittent related to specific factors or chronic. In severe cases, it is associated with cachexia (weight loss, muscle wasting).	Poor oral hygiene. Pain. Nausea. Medications. Constipation. Dysphasia. Depression and anxiety.	Identify and treat any reversible causes. Aim is to improve "quality of life" by aiming to a) Relieve nausea; b) Improve appetite; c) Maintain or increase weight; d) Identify the service user and family • Understanding of treatment aims and limitations. • User of anti-emetics for nausea. • Medication review. Nursing Considerations; • Address any underlying causes, e.g. oral hygiene needs; constipation. • Referral to dietician as appropriate. • Offer favourite foods as tolerated. • Administer medications and monitor effects. • Attend to pressure area care.

Symptom	Possible Causes	Assessment	Treatment Management
Nausea / Vomiting	Existing condition, e.g., renal/cardiac failure; diabetes; slowing of gastric motility	Eating and drinking habits. Lab values as ordered by GP/palliative care team. Medication review.	• Identify and address underlying cause. • Administer anti-emetics and other medications as prescribed and monitor effects. • Ensure bowl, tissue and water are available if the service user is able to rinse. • Offer small and frequent meals as tolerated. • Avoid strong smells at mealtimes. • Avoid fluid intake at mealtimes. • Provide/assist with oral hygiene care as needed. • Rise mouth with water. Clean with a soft toothbrush and toothpaste as tolerated. • Soak dentures. • If dysphasic – use moistened swabs. • Refer to Oral/Dental Care best practice.
• **Dry Mouth**	• Side effect of medications. • ‘Mouth breathing’ Poor fluid intake.	• Oral cavity assessment	• Investigate and address cause as far as is practicable. • Encourage fluids if able to swallow. • Address breathing difficulties as outlined above. • Saliva substitute/lubricant may be required – liaise with GP/Palliative Care Team. • Provide/assist with oral hygiene needs as above. • Observe for ulceration, soreness, blisters or Candida and liaise with GP/Palliative Care Team re: treatment.

Symptom	Possible Causes	Assessment	Treatment Management
Terminal Delirium	• Present in the terminal phase and may be due to: • Medications, • Electrolyte imbalance, • Liver/Renal failure, • Hypoxia/ Ischemia • Infection, Pain/Discomfort.	• Observation for signs of pain and discomfort, delirium and constipation.	• Promote a quiet, comfortable environment. • Familiar people may be reassuring such as family members and consistent staff members. • Administer medications as prescribed and observe and record effects. • Continue to monitor for signs of pain and discomfort and liaise with the team about this.

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