(NAME OF AGENCY)

Procedures Manual

Title: **CARING FOR A TERMINALLY ILL SERVICE USER**
(KLOE)

1.0 Scope

1.1 The practical and emotional support given to terminally ill Service Users, their relatives, carers and Home Care Staff.

2.0 Aims and Value

2.1 To ensure that the dignity of the Service User is maintained.

2.2 To respect the culture and religious beliefs of the Service User.

3.0 Contents

4.0 Referenced Documents

DC-009 Communication Record Sheet.
DC-054 Person Centred Care Plan.
QP-43 End of Life Care Plan.
MA-03 Infection Control.

5.0 Responsibilities

Management, all Home Care Staff and the Service User.

This is the procedure to be followed:

This procedure must be read in conjunction with the service's policy QP-43, End of Life Care.

6.0 END OF LIFE CARE PLAN

6.1 The End of Life Care Plan provides a plan of care for the dying Service User. The plan provides a palliative framework to aid the Service User in their last stages of life and includes symptom control management, psychological and spiritual care and family support.

6.2 The aim of the plan is to improve the quality of life of those Service Users who are at the end stage of their life. The plan should be created with input from the Service User their family, GP other health care professional involved, the Service User's key worker and staff. The development of the End of Life Care Plan should only be done through transparent actions and communications with all those involved.

6.3 The End of Life Care Plan should include:

- Assessment of care, treatment and support options.
- Symptom management including medications prescribed for pain, pain management, nausea, agitation and sleeping. It is essential that the service user's family is aware of the different types of medication and the circumstances where their use might be deployed.
- Where the Service User would like to end their days.
- Meeting personal preferences, religious and cultural needs and where the person wishes to die. These should be clearly recorded, communicated, kept under review and acted upon.
- Protected equality characteristics.
- Arrangements for monitoring the changing conditions in the Service Users Health and wellbeing in the last days of their life.
- Arrangements where required, that give people rapid access to support, equipment and medicines.
- Agreement with the service user's family and supporters to the plan.

6.4 The End of life Care plan should commence following consultation with the Service User's general practitioner, other health care professionals. family, carers, and advocates.

6.5 The Home Care Co-ordinator should follow along with the family and along with the Social Workers Care Managers should obtain written agreement to the plan (where practical) before commencement.

6.6 Before the plan can commence, the general practitioner must review all unnecessary interventions and sign the resuscitation and medication reviewed sections.

6.7 The plan should include arrangements to minimise unnecessary disruption to the care, treatment, support and accommodation of the person who uses the service, their family and those close to them.

6.8 Staff must ensure that plan is reviewed by the Service User's General Practitioner at regular intervals to see that it is meeting the Service User's needs and modified accordingly, and a record of such plan reviews kept on file.

6.9 Staff responsible, must ensure that the End of Life Plan is reviewed by the Service User's General Practitioner at regular intervals to see that it is meeting the Service User's needs and modified accordingly, and a record of such plan reviews kept on file.

7.0 IMPLEMENTATION OF THE END OF LIFE CARE PLAN

7.1 The Home Care Co-ordinator must ensure the implementation of the End of life Care Plan only commences on the advice of the Service User's GP.

7.2 The Home Care Co-ordinator should ensure that when they agree to provide End of life Care, the care manager is in a position to allocate sufficient staffing resources to meet the requirements of the plan.

7.3 Staff should receive training and supervision to ensure they have the required skills to meet the needs of the Service User End of life Care Plan.

7.4 Where appropriate, the Home Care Co-ordinator will make arrangements for Service Users to have access to the specialist palliative care services they need.

7.5 The Home Care Co-ordinator will ensure that the equipment required by the end of life care plan is made available to the Service User.

8.0 RECORDS

8.1 The Home Care Co-ordinator should ensure that staff keep detailed records of all matters relating to Service User's End of life Care Plan.

8.2 Staff responsible for the End of Life Care Plan will record any expressed preferences and choices in the persons End of Life Care Plan. All care plan interventions will take into account the protected equality characteristics of the Service User and where they wish to die. Staff must ensure that these are acted upon.

9.0 PRACTICAL CARE FOR THE TERMINALLY ILL

9.1 Staff must check the End of life Care Plan to establish the tasks to be undertaken. This may be a joint plan with Macmillan Nurses or other Health Service Agencies.

9.2 Home Care Staff should be aware of the following:

- The needs of the Service User may change as their condition deteriorates.
- Tasks may take longer.
- Moving and being moved will be more tiring for the Service User and may cause pain.
- Food and hot drinks may be refused.
- Frequent demands may be made for drinks or ice to refresh their mouth.
- Breathing may become difficult e.g. shallow, erratic.
- Physical changes may occur e.g. weight loss, skin condition.
- The Service User's mental state may change e.g. hallucination, confusion.

9.3 Where staff become aware that death of a Service User is imminent, staff should carry out the following procedure.
Staff should ensure that the Service User is:

- Clean.
- Comfortable.
- Warm.
- Given appropriate lighting in the room.

9.4 Staff should ensure the Service User's privacy; dignity and respect are maintained (being aware that any remarks will still be heard).

9.5 Staff should see that the Service User's possessions are at hand, should comply with the expressed wishes of the Service User and ensure that the Service User is not left alone.

9.6 Where required, staff will consult with palliative care services; general practitioners about any specialist equipment that the Service User will need to aid their comfort and promote dignity in the end stages of life.

10.0 EMOTIONAL SUPPORT FOR A TERMINALLY ILL SERVICE USER AND THEIR RELATIVES

10.1 Home Care Staff should be aware of the following:

- Be sympathetic but not sentimental to both the Service User and the family.
- Try to maintain a relaxed and normal atmosphere.
- Allow the Service User and family time to talk about fears and anxieties whilst remaining impartial.
- Respect the culture and religious beliefs of the Service User and their family.

11.0 SUSPECTED SUDDEN DEATH OF A SERVICE USER

Only a qualified medical practitioner can certify that a Service User has died. Staff who are faced with a situation where a Service User appears to have died should refer to the Service User as "a suspected death".

11.1 If when visiting staff find a Service User appears to have died, whether very recently or some time earlier, staff should:

- Immediately phone the Home Care Co-ordinator and Service User's GP and inform them of the "suspected death".
- Not try to move the Service User until permission has been given by the GP or police.
- Not touch any of the Service User's possessions other than to make safe a potential hazard (e.g. switch off fires, kettles, ovens etc).
- Never remove anything from the property.
- Ensure that the property is left in a safe and secure condition.

11.2 The Home Care Co-ordinator must notify the next of kin, This should be done in a sensitive way following guidelines shown below:

- Try to avoid using the telephone to inform a relative that the Service User has died unless absolutely necessary.
- Think about whether there is another person who might be better able to do this who is less emotionally involved.
- Think about the distance the relative must travel and the time this might take. It is not safe for a person in a distressed state to rush to the home over a great distance if the Service User has been certified as dead.
- Staff should be available to supportive relatives at the Services Users home where appropriate.
- Where the Service User has no Known next of kin, the Home Care Co-ordinator must notify the Service Users social worker or relevant social work department to make funeral arrangements.

11.3 Where Service Users have no known or declared next of kin, the Home Care Co-ordinator should contact the local Social Services Duty Officer who is responsible for arranging the removal of the deceased service user and any other matters relating to the situation.

11.5 There should be a record of the ethnic, religious or spiritual needs surrounding the death of a Service User. The Home Care Co-ordinator should ensure that the body of the deceased person is cared for in a culturally sensitive and dignified way by staff and the funeral director.

12.0 ACTIONS TO BE TAKEN BY STAFF IN RELATION TO INFECTION CONTROL

12.1 Where the Agency has a responsibility. Following confirmation by the GP of the death of a Service User, and before carrying out the last caring duties for the Service User the manager must ensure staff follow the requirements of the infection control procedure MA-03.

12.2 Depending on the circumstances it may be necessary to carry out a risk assessment to identify any potential hazards and ensure safe working practices in relation to infection control.

13.0 WHAT HOME CARE STAFF SHOULD DO IF PROBLEMS ARISE

- You are concerned about the changes in the Service User's condition.
- You do not feel able to cope with the practical or emotional demands of the Service User or their relatives.
- You need additional time to complete the tasks detailed in the Person Centred Care Plan, DC-054.
- The Service User appears to have died.

Contact your Home Care Co-ordinator for support and advice.

Remember to record all actions undertaken on the Communication Record Sheet, DC-009, within the Person Centred Care Plan, DC-054.

Guidance for managers

What the Care Quality Commission requires

Key Lines of Enquiry 2018 - **Responsive R3: How are people supported at the end of their life to have a comfortable, dignified and pain-free death?**

Prompt	Compliance Evidence
R3.1 Are people's preferences and choices for their end of life care and where they wish to die, including in relation to their protected equality characteristics, spiritual and cultural needs, clearly recorded, communicated, kept under review and acted on?	Para 8.2 of this procedure addresses the prompt
R3.2 How are people, and their family, friends and other carers, involved in planning, managing and making decisions about their end of life care?	Para 6.2 of this procedure addresses the prompt
R3.3 How are people reassured that their pain and other symptoms will be assessed and managed effectively as they approach the end of their life, including having access to support from specialist palliative care professionals, particularly if they are unable to speak or communicate?	Para 6.3, 7.4 and 9.6 of this procedure addresses the prompt
R3.4 How does the service make sure that it quickly identifies people in the last days of life whose condition may be unpredictable and change rapidly and, where required, that	Para 6.3 of this procedure addresses the prompt

people have rapid access to support, equipment and medicines?	
R3.5 How does the service support people's families, other people using the service and staff when someone dies?	Section 11.0 of this procedure addresses the prompt
R3.6 What arrangements are there for making sure that the body of a person who has died is cared for in a culturally sensitive and dignified way?	Para 11.5 of this procedure addresses the prompt

Managers will need to demonstrate to CQC that they are complying with the regulation and Fundamental Standard by following the procedure or policy that provides the evidence.