‘Doing it my way’

STANDARDS ON END OF LIFE CARE FOR PEOPLE WITH LEARNING DISABILITIES

Part of the comprehensive guide for health and social care staff

A life without limits for the people we support

ST ANNE’S
COMMUNITY SERVICES

St Anne’s Community Services is a Registered Charity,
Number 502224, registered Provider (Social Housing, number H3158)

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE

Moving into a home/service

CARE STANDARDS

S1. Identification of needs including potential Life limiting Conditions (LLCS):-

People with Learning Disabilities have genetic disorders or congenital abnormalities.

Most PLD have many Life limiting Conditions.

The uncertain prognosis of such LLCs means most PLDs need supportive palliative care throughout their life as well as specialist palliative and EoLC when they are nearing death.

LLCs for PLD include:
- Down's Syndrome
- Cerebral Palsy
- Respiratory disease
- Diabetes
- Severe mental health
- Cardio-vascular disease
- Epilepsy

CARE STANDARDS GUIDELINES

Getting the staff team on board with care planning

When a person with a learning disability moves into a nursing home, or a residential home, the management, the nursing staff and the support staff must work in collaboration with other health and social care professionals involved in the person's care.

The aim is to ensure that accurate and up-to-date details about their diagnosis, including any LLCs, are identified when they move in and are stated in the referral or moving-in documents.

Contact details of the family members and any other professional teams involved in the person's care must be included in the moving-in documents.

This will enable the future planning and delivery of quality care throughout the person's life and at the dying phase and death.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
Moving into a home/service	S1.Identification of needs including potential Life limiting Conditions (LLCS) continues: • Swallowing difficulties • Irritable bowels and vomiting linked to the helicobacter pylori bacteria, especially common in people with Down’s syndrome.	Getting the staff team on board with care planning When a person with a learning disability moves into a nursing home, or moves to a residential home, the management team, the nursing staff and the support staff must work in collaboration with other health and social care professionals involved in the person’s care. This should continue throughout the life of the person until their death.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
Moving into a home/service	S2.Communication Good communication is key to coordinating activities between the learning disability team, family members, and other health and social care professionals, including supportive or specialist palliative care professionals involved in caring for the person.	Getting the staff team on board with care planning When a person with a learning disability moves into a nursing home, or moves to a residential home, the management team, the nursing staff and the support staff must work in collaboration with other health and social care professionals involved in the person’s care. This should continue throughout the life of the person until their death. To ensure good teamwork, and well planned and co-ordinated care, it is important that there’s regular communication between all professionals, both within the home where the person with a learning disability resides and with external service providers. This should include an agreed forum for verbal communication between all relevant professionals, and also the sharing of up-to-date written documentations. This will ensure both consistency and continuity in the person’s daily and advanced/future care.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
Moving into a home/service	S3. Multidisciplinary Team (MDT) and collaborative working continues: MDT includes: the manager, the nursing and support staff team; family members; health and social care professionals involved in the care of the person with a learning disability. Collaborative working entails efficient team-working amongst the nursing staff team, residential care team, family members and other health and social care professionals involved in the person’s care.	Getting the staff team on board with care planning Good networking between the nursing staff team, residential care team, family members and other health and social care professionals will help in meeting all the present needs of the person, thus improving the quality of care throughout their life and at the dying phase and death. At this stage, it may be necessary for all the MDT members to discuss about the person’s health and life and how to plan any future care. Discussions may include: Advanced Statement, Advanced Care Plan, Advanced Decision, and DNACPR. Records about the person’s religion, spiritual and cultural needs should be included. (See the ‘Doing it my Way Comprehensive Guide on End of Life care’) The aim is to ensure consistency and continuity in the person’s care. At this stage, the role of the GP is very significant in coordinating monthly health checks and reviews.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
Planning Stage	S4. Effective Planning and Recording: Care Planning must be based on person-centred care Effective care planning includes daily care, supportive and specialist palliative care.	The care of a person with a learning disability must be person-centred from the moment they move into a home and throughout all care decisions. All documents need to include a Care Support Plan incorporating particular key factors with the goal of promoting effective planning. This will ensure quality care throughout the person’s life to the time of their death. The Care Support plan must consider the person’s life expectancy in terms of the state of their optimum health, their congenital abnormalities, any diagnosed LLC that either does or does not respond to treatment, and if the person is showing symptoms of being in the final stages of life. At this stage discussions must include: Advanced Statement, Advanced Care Plan, Advanced Decision, and DNACPR. Records about the person’s religion, spiritual and cultural needs should be included. (See the *‘Doing it my Way Comprehensive Guide on End of Life care*‘). The aim is to enable learning disability staff teams, health and other social care professionals to anticipate the client’s needs and plan care accordingly. The Care Support Plan must show an agreed period or timescale for regular reviews of the person’s care. Depending on their health or diagnosed condition, and the progression of their condition or disease, such reviews could be monthly, or less.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
Implementing Stage: Implementing care consists of various stages: When the person with a learning disability has optimum health.	S5.Implementing care: Apart from daily care delivery in the life of the person with learning disabilities, there are other crucial stages which affect the planning, coordination and implementation of care. These specific stages should clearly state the progression of the person’s disease. This means minimal intervention or care is needed.	Notwithstanding the complexity of care required, the care of a person with a learning disability must be person-centred,taking into consideration the whole person in terms of their physiological,spiritual,and psycho-social needs. Also,any care provided must take into account any ethical issues such as dignity,choice and compassion. Discuss Advanced Care Planning: This is to ensure that: - Care staff must also consider if the person has epilepsy,or congenital abnormalities such as cerebral palsy, hydrocephaly, Cystic Fibrosis,and chromosomal abnormality,for example, Down’s Syndrome. These conditions may affect their life expectancy and sudden death incidents may occur.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE

Implementing Stage: Implementing care consists of various stages:

When the person with a learning disability is diagnosed with a Life Limiting Condition

CARE STANDARDS

S5 Implementing care continues:

Apart from daily care delivery in the life of the PLD, there are other crucial stages which affect the planning, coordination and implementation of care. These specific stages should clearly state the progression of the person’s disease.

LLCs for PLD include: -

- Down’s Syndrome
- Cerebral Palsy
- Respiratory disease
- Diabetes
- Severe mental health
- Cardio-vascular disease
- Epilepsy

*NOTE:
Some LLCs may respond to treatment. For example: Cardio-vascular disease, Multiple Sclerosis, HIV/AIDS, Kidney failure needing dialysis, and certain forms of cancer.

CARE STANDARDS GUIDELINES

Team working between and amongst the residential staff team, nursing staff team, family members, other health, and social care professionals is crucial.

All documents need to be reviewed with a current Care Support Plan indicating the particular diagnosis of the life-threatening condition(s) and the symptoms. (*See P.1 of this document for LLCs*).

The Care Support Plan must also show how the person’s dignity and choices at this stage of their life are being promoted, how their spiritual and cultural needs are incorporated in their care, and evidence of kind-hearted i.e. (compassionate) care.

There must be ongoing review of the Care Support Plan and all risk assessments.

The Care Support Plan must also show accurate details of any Anticipatory medication i.e. (‘*just in case medication’*), which has been prescribed for EoLC and held in stock at the place where the person with a learning disability is based.

The goal here is to ensure effective planning to enhance quality care that reflects the person’s changing health, physiological, spiritual, and psycho-social needs.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
Implementing Stage: Implementing care consists of various stages: When the person with a learning disability is diagnosed with a specific age-related, life-limiting condition such as Dementia.	S5.Implementing Care continues: Apart from daily care delivery in the life of the PLD, there are other crucial stages which affect the planning, coordination and implementation of care. These specific stages should clearly state the progression of the person’s disease.	All documents need to be reviewed. The current Care Support Plan must show evidence of empathetic care, how the person’s dignity and choices at this stage of their life are being promoted, and also, how their spiritual and cultural needs are included in their care. The Care Support Plan should state an audit trail of specific training on dementia care by the staff team to meet the needs of the person. Collaborative working with other specialist is vital to promote quality care.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
Implementing Stage: Implementing care consists of various stages: When the Life Limiting Condition becomes progressive or terminal	S5.Implementing care continues: Apart from daily care delivery in the life of the PLD, there are other crucial stages which affect the planning, coordination and implementation of care. These specific stages should clearly state the progression of the person’s disease. When the LLC becomes terminal it means that the disease does not respond to treatment. The person’s condition will deteriorate and they will experience a reduction in their ability to independently manage their own needs. See:(‘Doing it My Way: POLE’ document) for examples of what to expect.	When the LLC becomes terminal, an Initial Advanced Care Planning relating specifically to EoLC must be included in the person’s Care Support Plan: See the document: *‘My Advanced Care Plan’* Include family members, the learning disability staff team and other health and social care professionals in all discussions and decisions. Work closely with the GP, District nurse, local palliative and out –of-hours sevices. Discussions must include these issues: • Symptom control • Resuscitation status • Reduced trips to hospital • Out of hours continuing care • just in case’ medication prescribing • Supporting relatives *End of life support. See:(*‘Doing it My Way: Comprehensive Guidelines for EoLC’*) for more explanation of these issues). The Care Support Plan must show issues relating to informed consent, best interest decisions with the appropriate MDT where necessary, and discussions and clear decisions around DNAR. The Care Support Plan must also indicate the staff awareness, skills or necessary training undertaken to promote person-centred care that includes informed consent, best interest decisions, dignity, choice, comfort, courage and compassion.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE

Implementing Stage: Implementing care consists of various stages:

End of Life Support:

This means care in the final days of the person’s life.

CARE STANDARDS

S6. Facilitating the Preferred Place of Death and Reducing Hospital Admissions

It may be difficult to decide when a person is approaching their final days because the symptoms vary from person-to-person.

However, here are some of the common symptoms experienced by a person near the end of their life:

- Drowsiness
- Becoming unresponsive
- General confusion
- Loss of appetite
- Loss of bladder and bowel control
- Skin becoming cool to the touch

Laboured, irregular or noisy breathing. See both the *‘Doing it My Way: Pole document and the Comprehensive Guidelines’* about how to manage these symptoms.

*It is important for someone to be with the person during this time to provide comfort. Even though he or she is dying they may still be able to sense your presence.

CARE STANDARDS GUIDELINES

Communication and collaboration is vital amongst the residential or support staff team, the learning disability nurses, the district nurses, the GP, local palliative and out –of-hours services, and all other health and social care professionals involved in the person’s care.

All documents need to be reviewed. At this stage, the current Care Support Plan must indicate the person’s preferred place of care as agreed with family members and other health and social care professionals involved in the person’s care, under best interest decision policy.

The Care Support Plan must also show the steps in place to ensure quick hospital discharge.

Plus, it must also demonstrate how adequate support has been provided to residential or support staff teams who may be struggling with the situation.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
Implementing Stage: Implementing care consists of various stages: Care in the final days of the person’s life	Continuation of S6 Facilitating the Preferred Place of Death and Minimising Hospital Admissions	The Care Support Plan must indicate the particular diagnosis of life threatening condition(s), the symptoms and management of the symptoms. This should include evidence of *‘just in case medication’* or anticipatory prescribed medication and accurate details of out-of-hours contact with the GP and palliative care professionals. The aim here is to ensure effective planning and evidence of quality care that reflects the person’s changing health, physiological, spiritual, and psycho-social needs. A Secondary Advanced Care Planning relating specifically to EoLC should be included in the person’s care. Include family members, the staff team and other health and social care professionals in all discussions and decisions. The Care Support Plan must show issues relating to informed consent, best interest decisions with family members, and the appropriate MDT where necessary and also state clearly, decisions around the preferred place of death, DNAR, and death rites.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
Implementing Stage: Implementing care consists of various stages: Care in the final days of the person’s life	Continuation of S6 Facilitating the Preferred Place of Death and Minimising Hospital Admissions	The Care Support Plan must show issues relating to informed consent, best interest decisions with family members and the appropriate MDT where necessary, and also state clearly, decisions around the preferred place of death, DNAR; death rites, the type of burial and place, and the type of funeral. A Final Advanced Care Planning relating particularly to EoLC should be included. This relates to keeping an accurate and up-to-date audit trail that records the ongoing changes in the person’s health, the care needed, the curative medications discontinued or the PRN medication introduced for pain management. It should also clearly state if any specific End of Life Care Path Way has been adapted. Also, the needs of the staff team and family directly involved in the person’s care must be considered.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
Implementing Stage: Implementing care consists of various stages: Care in the final days of the person’s life	Continuation of S6 Facilitating the Preferred Place of Death and Minimising Hospital Admissions	The work of the staff team should focus on meeting any identified training needs in terms of skills required to provide EoLC for the dying person. At this stage, it is important that contact, collaboration and focused, person-centred discussions are maintained with all the professionals involved in the person’s care. Especially, the specialist palliative care team members who will provide the necessary supportive training to the residential staff team, as well as to any learning disability nurses involved in the person’s care. This is in terms of skilled clinical care the dying person may need. Where the person’s preferred place of death is either in the residential home, supported living, or even a nursing home, the Care Support Plan must also show how Verification of death will be undertaken.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE

Implementing Stage: Implementing care consists of various stages:

The death of a person.

CARE STANDARDS

S7. Dealing with the death of a person

If you think that a person has died, you must do one of the following:

- If the person does not have a DNACPR in place, call an ambulance (999) and start resuscitation.
- If the person does have a DNACPR in place, do not call 999, call the person’s GP or out-of-hours services. If they are not available then phone emergency services.

CARE STANDARDS GUIDELINES

It can be very upsetting to family members, staff and other individuals in your care when a person dies.

As a staff member or team, it is alright to be upset but it is very important to remain professional as there are a number of things which need to be done:

- Phone their GP right away and explain what has happened.
- If it is out-of-hours and the person does not have a GP, call 999 and wait for emergency services. Make sure the area is left undisturbed.
- A GP or another qualified medical practitioner will have to come and certify the death, and the person’s body will be taken away.
- Funeral arrangements have to be made. If the family want to do so, you need to give them the death certificate so that they can register the death. If not, then you should do it.
- All the person’s medication and medication records should be kept for a minimum of 7 days in case there is a coroner’s inquest.
- Inform family members as soon as possible. They may want to say their goodbyes or pray before the final arrangements. Offer counselling services to both staff and family members.
- The Advance Care Plan of the person’s preferences, both cultural and religious, must be adhered to as a sign of respect and dignity.

Standards on End of Life care for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
Aftercare and after death arrangements	S8. Dealing with issues after death After the death of the person with a learning disability the ongoing record of changes in their condition (known as the audit trail) used during the course of their illness (known as the disease trajectory) ought to be reviewed. This will identify any issues that other clients or the staff team might have especially, around bereavement. Remember, you may need to do a number of things at this critical time so it is important to remain professional.	Include family members, learning disability residential staff team, palliative care team, and other health and social care professionals who had cared for the deceased in all after-death discussions and reflections. The goal is to gather valid data about what support may be required by other people in your care, their family and your staff. • Identify a member of staff who has good relationship with the family as a point of contact to liaise with them about funeral plans or memorial services. • Send a sympathy card. • Offer support in funeral arrangements and liaise with the funeral director and family. • Offer the family the option to set off to the funeral from the home of their loved one. • Send a wreath or donation making sure you adhere to the wishes of the person or their family. • Offer the family the option to have the funeral tea at the person’s home. • Enable other people in your care to go to the funeral if they wish. • Offer support to the family around the person’s estate where necessary • Have an annual remembrance service either in the home or in the grounds

Palliative and End of Life Care Standards for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
What Next?	S9.Reflection and Competence Building After the death of the person with a learning disability the ongoing record of changes in their condition (known as the audit trail) used during the course of their illness (known as the disease trajectory) ought to be reviewed. This will identify any issues that other clients or the staff team might have especially, around bereavement.	Include family members, learning disability residential staff team, palliative care team, and other health and social care professionals who had cared for the deceased in all after-death discussions and reflections. The goal is to gather valid feedback and information about the care the person experienced before their death. Positive feedback will provide reassurance to the staff team. If negative, it will serve as a guide to help improve your quality and standards of care, and also identify potential areas for further palliative and EoLC training. It may be difficult to get used to the home without the person around. However, over time, it will get easier for both the staff team and the other people in your care. Also knowing that you did the best to provide a good death for the individual will help prepare you for similar situations in the future.

Palliative and End of Life Care Standards for People with Learning Disabilities

STEPS IN PLANNING CARE	CARE STANDARDS	CARE STANDARDS GUIDELINES
What Next? Further Information This document is part of the End-of-Life care package for social care staff caring for people with learning disabilities. Other documents in the series include: • Probabilities of Life Expectancy (POLE) • Doing it My Way: A comprehensive guide of End on Life care for people with learning disabilities. • DVD • Training package, • ’Supporting your relative throughout the whole of their life’ leaflet.	S10. Continuity To promote inclusive care, this document and the associated tools will help both social care professionals, other healthcare professionals and learning disabilities staff to support people with learning disabilities throughout their lifespan and at the end of life.	Social and healthcare professionals who have adapted this guidelines and related tools to provide palliative and EoLC to people with learning disabilities can contact the originators of this document for further advice.

Glossary of Abbreviations and Terms as first used, and throughout this Document

PLDs: People with Learning Disabilities - page *02*

LLCs: Life Limiting Conditions - page *02*

EoLC: End-of-Life-care - page *02*

Prognosis: means diagnosis - page *02*

Genetic or congenital abnormalities: means abnormalities that are hereditary, or present at birth - page *02*

MDT: Multi-disciplinary Team - page *05*

Advance Care Plan: means Future care or planning ahead - page *05*

Advance Decision: It is a legal binding document, which sets out what the patient does not want to happen at the end of life stage of their lives - page *05*

Advance Statement: Like the Advance decision: it sets out what the patient what the patient wants or does not want to happen at the end stage of their lives - page *05*

DNACPR: Do Not Attempt Cardio-Pulmonary Resuscitation - page *05*

Anticipatory Medication: ‘just in case medication’, which has been prescribed to be used at the End-of-life care stage - page *08*

Best Interest Decision: means a decision made on behalf of someone who cannot make their own decision. It is done in accordance with Mental Capacity Act 2005. It involves the family and all professionals involved in the care of the patient/client - page *11*

PRN Medication: Medication that is prescribed to be given only when needed such as pain relief - page *13*

Disease Trajectory: refers to the course of an illness - page *16*

Audit trail: refers to the ongoing record keeping of the assessments, re-assessments, and review of the client’s care during the course of their illness until the time of their death - page *16*

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