Policy / Procedure Details	Title:	**End of Life Care**
	Type:	**Services**
	Related Personal Outcome Measure:	**I experience Continuity and Security**
	Code:	**2A.14**
Original Version Details	Date Released:	**10 / 06/ 2016**
Current Version Details	Written By:	**Social Work Department and Evaluation and Training Department**
	Reviewed By:	**Leadership Team**
	Approved By:	**Executive Director**
	Date Released:	**10 / 06/ 2016**
	Monitoring Process:	**Procedural Review Process**
	Date Due for Review:	**10 / 06/ 2019**

End-of-Life Care

These guidelines are to act as a support to staff caring for a person approaching the end of their life.

People who are approaching the end of their life need high-quality treatment and care that support them to live as well as possible until they die, and to die with dignity.

People are approaching the end of life when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

(a) Advanced, progressive, incurable conditions.
(b) General frailty and co-existing conditions.
(c) Existing conditions leaving them at risk of dying from a sudden acute crisis in their condition.
(d) Life-threatening acute conditions caused by sudden catastrophic events.

End-of-Life care is defined as care that *"helps all those with advanced progressive incurable illness to live as well as possible until they die. It enables supportive and end-of-life care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support"* (National Council for Palliative Care, 2006). The provision of emotional support is also central to effective practice in this area.

This policy is based on the NHS document "The route of success in the end of life care – achieving quality for people with learning disabilities". Direct quotations from this document are placed in italics. The full document is available on http://socialwelfare.bl.uk/subject-areas/services-client-groups/adults-mental-health/nhsnationalendoflifecareprogramme/routetosuccess11.aspx

Policy Scope: This policy sets out provision for staff to follow when supporting an individual coping with a terminal illness and the various decision points that will arise in that journey. It is a complementary policy to the "Loss and Bereavement Policy"; (Western Care Policy – 2A.13) which describes best practice in support of an individual experiencing bereavement. It is also a complementary policy to the "Managing and Reporting a Death in Service Policy"; (Western Care Policy – 2A.15)

Policy Application: This policy applies in the main for individuals that are in receipt of fulltime residential supports from Western Care. Where individuals are living at home with their families, then staff should liaise with social work to ensure that the principles set out in the guide are followed but in an individualised way to each situation.

Policy Tools: Throughout this policy, there will be references to an **End of Life Plan**. This document serves to pull together important decisions in relation to how best to respond to issues arising when a person is living with a life limiting condition and to record the individual and their families' preferences in relation to how end of life support will be provided. It will also record preferences in relation to funeral arrangements so these can be known and followed.

The End of Life Plan does not replace the **Health Action Plan** which should continue to be used to record the person's medical conditions, attendance at various appointments and the conduct of various investigations and their outcome.

Staff will need to maintain both documents on file to support them in the provision of care and support to individuals living with a life limiting condition.

Step 1: Discussions as the end of life approaches

Identifying when people are approaching the end of their life can be very complex. In the case of people with learning disabilities, the late presentation of serious illness, limited verbal communication and service settings which are not used to dealing with physical ill health can all exacerbate this. To ensure that people with learning disabilities get the best end of life care possible it is important to develop partnerships across all settings with both formal and family carers. One of the key challenges for staff and family member is to know how to develop sensitive and open conversations with people with learning disabilities who are nearing the end of life. These conversations need to take account of the person's preferred communication style, their cognitive abilities, their understanding of language, serious illness death and dying as well as their concept of time.

Issues to consider:

- *Given the person's understanding of their illness, their concept of time and their communication style, consider carefully whether and when it is appropriate to open a supportive discussion about their wishes for the end of life.*
- *Remember that even people with a mild learning disability may understand language in a literal, non-euphemistic manner and therefore anything that is communicated should take account of this. For instance, avoid the use of abstract language in discussions about end of life (e.g. talk about "dying" rather than "passing away").*
- *It may be better to have a number of short, single focus conversations than to try and communicate everything in one session.*
- *Family members may need support to overcome their natural instinct to "protect their loved one from the knowledge of the diagnosis or prognosis.*
- *Take into account the environment in which discussions about end of life care are to be held. Remember that for some people, environments that are noisy, very bright or have strong smells associated with them may initiate a sensory overload which can impeded their ability to understand the information being imparted. For other people, previous traumatic experience of healthcare may make them nervous of staff in uniforms or of certain procedures; e.g. those involving needles.*

Staff should:

- Use the **Health Action Plan** to monitor any increase in the person's symptoms and to determine a change in their condition.
- Work with the GP and other involved medical staff to follow up on medical investigations so that a clear diagnosis can be made.
- Work with the person's circle of support to identify how best to inform the person when a life limiting condition has been diagnosed.
- Consider how medical information can be communicated in keeping with that person's communication preferences.

Step 2: Assessment Care Planning and Review

An early assessment of the person's needs and wishes as they approach the end of life is vital to establish their preferences and choices as well as identifying any area of unmet need. It is important to explore the physical, psychological, emotional, social, spiritual, cultural and where appropriate environmental needs and wishes of each individual. People with intellectual disabilities are likely to have the same range of opinions regarding treatment decisions and end of life care options as the general public. Assumptions should not be made as to what these are likely to be but, rather, timely, sensitive and consistent support should be given to each person as needed.

The tool to support this work is the **End of Life Plan**. This Plan sets out what a person wishes to happen as someone approaches end of life. It is done in order to ensure that the wishes of the person are honoured at a critical time in their life. A sample template is included in the Appendix.

The following questions should be considered in developing a plan with someone:

a) What is right for the person? What are their values and beliefs about end of life? What is important to them?
b) Who will make decisions for the person, honouring their wishes and speaking on their behalf if they cannot themselves?

The Plan should contain the following:

- How will the person be supported to remain in familiar surroundings with familiar people?
- How will their treatment be managed? i.e. what treatments will benefit the person?
- Is there any means by which the person's physical and emotional distress is assessed and recorded; eg, DisDAT? Has this documentation already been completed and is it accessible to all those involved in the person's care? Is it reviewed regularly, not just in times of crisis?
- How will pain be managed?
- If the person has a terminal condition, should they be resuscitated if their heart stops beating?
- How will hydration and nutrition be managed?
- Does the person have religious, spiritual or cultural needs to be met when dying? Additional resources are available from the social work department in relation to specific cultural and religious traditions in this area.
- What sort of funeral would the person want?

Any plans that are developed with a person should be done by those who know and care about them e.g. Circle of Support. All plans should be informed at all times by the medical advice of the health professionals involved. If a disagreement arises then the Circle of Support should endeavour to reach a consensus honouring the wishes of the person. If this is not possible, then it may be necessary to consider independent advocacy or legal advice.

Step 3: Co-ordination of Care

Once a care plan has been agreed it is important that the services needed are effectively co-ordinated. This can be particularly complex in the case of people with learning disabilities who may have a number of agencies involved in their lives. It is therefore vital at an early stage to establish good systems for communication and appropriate transfer of information across settings in keeping with the service user's wishes.

As the service user's condition deteriorates there is need for a regular review of communication and team working and a willingness for different members of the team to take the lead (or become the key worker) as best befits the needs of the person. This means that at times it will be most appropriate for this to be a member of learning disability staff but at others (perhaps in the later stages of an illness), for a member of palliative care staff to take on this role. Carers are a key component of any team and consideration needs to be given to the needs of family carers (who in the case of someone with a learning disability may have been carers for decades)

Issues to consider:

- It is important that everyone involved in the care of the person remain informed of the evolving end of life care plan. The Named Staff will be able to play a key role in coordinating between those services involved but also in keeping family carers and friends up-to-date with the emerging situation in keeping with the person's wishes.

- Staff should understand that as the person's condition changes, it may be necessary to formally review the End of Life Plan with the Circle of Support involved.

Step 4: Delivery of high quality services in different settings

In the last year of life, service users and their families may need access to a complex combination of services across a number of different settings. They should be able to expect the same high level of care regardless of where they are being looked after. A number of people with learning disabilities will be significantly younger than the general population of dying people and may have multiple long-term physical and psychological problems which may make their care and access to appropriate end of life care placements complex. For some learning disabled people, living in their own home will have been a great achievement and they will naturally want to stay there irrespective of the inadequacies of their care package. Therefore the care team will need to be cognisant of this in balancing assessments of `risk' alongside a need to fulfil, wherever possible, the last wishes of the dying person.

Issues to Consider:

- Staff will need to ensure that the environment within which the service user lives offer privacy, dignity and respect for individuals, their families and friends as end of life approaches, or that it can be adapted to do so.

- Consideration may need to be given to the fact that the care needs of the individual become too complex to be managed in their current setting, an alternative arrangement may need to be put in place.

- Any decision with regard to a change to the setting the person lives in or provision to transfer to another setting should be made by the person and their **Circle of Support.** It set out in the End of Life Plan.

- Don't forget the role that other service users who have a close relationship with the person who is dying may play in delivering their end of life care. As the individual's condition deteriorates they may require support to continue to play an active part in the care. As this will positively influence their bereavement experience they should be helped wherever possible to do so. Attention in particular should be paid to those friends who are very close and may have been involved in the person's life over many years. Further information on this matter is set out in the "Loss and Bereavement Policy" (Western Care Policy, 2A.13)

- Staff should to help the individual maintain the maximum level of independence, choice and control for as long as possible.

Step 5: Care in the last days of life

There comes a point at which the person enters the dying phase of their illness. In the case of people with learning disabilities this often appears to happen suddenly with little warning, but for many others it can be a gradual process and therefore regular review (by the extended team) is crucial to determine when the individual has entered this phase.

Recognition of the dying phase is very important so that appropriate actions can be undertaken to ensure this process is well supported for the individual, family, friends and staff. How someone dies remains a lasting memory for the individual's relatives and friends and the care staff involved – it can impact greatly (both positively and negatively) on their bereavement experience as well as on how able staff are to continue to do their job in the future.

Issues to Consider:

- Staff should link with the GP and any palliative care services involved to ensure that they are fully informed of the changes which may occur in an individual's condition during the dying phase and how best to respond to these.

- The individual may have indicated specific wishes or preferences for this time, these should be set out in the End of Life Plan.

- Staff need to ensure that they have responded to any particular spiritual or cultural needs that have been recorded in the End of Life Plan.

- Medical staff may make a multi-disciplinary decision for the individual in relation to their acute medical needs. This can then act as a trigger to review whether the individual's end of life care needs and wishes can best be met in their current setting. As noted above under Step 4, in this situation, any decision with regard to a change to the setting the person lives in or provision to transfer to another setting should be made by the person and their **Circle of Support.** It set out in the End of Life Plan.

- Consider ways to support any family, friends or fellow service users that the individual wants to be present. For example, by providing, where possible, transport, accommodation, meals and emotional support. Liaise where necessary with those who support friends or family members who have a learning disability to ensure they are able to be as present as they and the dying person wishes them to be.

Step 6: Care after death

Good end of life care does not stop at the point of death. When someone dies all staff need to follow good practice for the care and viewing of the body as well as being responsive to the wishes of family and friends. The support provided to relatives will help them cope with their loss and is essential to achieving a 'good death'. This support is also important for staff and other service users.

When the person who has died is a person with a learning disability there may be specific issues for family members due to the impact of the disability which may have affected individual emotional attachments and the whole structure of the family's life. This is likely to be particularly so if the learning disability is severe or has been accompanied with physical disability; in many cases the family will have lived with the prospect of the person's death for many years.

Where those who are left behind include people with a learning disability, then particular care needs to be taken to ensure they are supported to be as fully involved as they would wish to be; particular care needs to be given to the bereaved person's previous experience of death and the sense they have made of this.

Issues to Consider:

- Staff may need to support discussions concerning the death already taken place with other service users? Is there an awareness of those most likely to be vulnerable to complex grief due to previous experience or levels of understanding? Is there a plan in place to support them? Further information on this matter is set out in the "Loss and Bereavement Policy" (Western Care Policy, 2A.13)

- There will need to be a clear plan to communicate the death to family members and other persons of significance bearing in mind that some of these may also have a learning disability and additional needs associated with this?

- Staff will need to consider sources of bereavement support (including those specifically for people with learning disabilities) been identified and followed up.

- Staff should respect individuals' faith, beliefs and preferences, taking steps to meet their requirements.

- Within a comfortable environment, facilitate the safe expression of other service users' questions, thoughts and feelings about the death.

- Staff may need to help family members to understand that the relationships between service users may have been very strong and might actually have been developed over significant periods of time in various service settings. Whilst it is a normal inclination for family members to 'protect' their learning disabled loved ones from the knowledge and impact of bereavement this is likely to result in exclusion and to have an adverse effect on their grief. Therefore, staff should be prepared to share knowledge about healthy grief and the evidence that it is facilitated through supported involvement in the rites of passage (e.g. funeral attendance) and, where necessary, to advocate in the best interest of the service user.

- Staff may also wish to provide families with sources of support following bereavement. Useful contact organisations include:

  - ✓ Barnardos Bereavement Service. Also excellent online supports.
  - ✓ First Light. Again excellent website.
  - ✓ Feileacain (Still Birth and Neonatal death).
  - ✓ Irish Childhood Bereavement Network.

- Clergy and funeral directors may not be aware of the need to use literal, non-euphemistic language to aid understanding in dealing with a bereaved person who has a learning disability; e.g., the need to say 'died' rather than 'passed away'.

- People with learning disabilities are more likely to need a concrete focus for their remembering and therefore photographs and objects related to the deceased person are of great importance. This is especially so in settings where the person's dwelling may need to be reallocated in the short term.

- It will not always be possible to tell in the short term who the death has had the most significance for. Some people with learning disabilities may appear relatively unaffected immediately after the death but six months or one year later may begin to express distress or depression related to the loss

- Deep distress as a result of bereavement may be expressed as challenging or self-injurious behaviour as well as in withdrawal, sleep deprivation or loss of appetite

- It will not always be necessary for people to verbally converse with a trained counsellor. There are a range of nonverbal therapeutic supports that may be suitable depending on the individual's situation. Staff should follow up with social work to get advice on the best approach. Further information on this matter is set out in the "Loss and Bereavement Policy" (Western Care Policy, 2A.13)

End of Life Template and Sample Completed Form

This is to inform the reader that the Circle of Support have put together some thoughts with regard to end of life planning for__________. This information is held confidentially and can be accessed through the person in charge.

End of life Planning for____

Date Plan Developed:
Date Plan Reviewed:
Who participated in the development of this plan?

1. ***What is the person's own view about death and dying?***
2. ***What are the person and their family's thoughts with regard to how best to support this person's care needs?***
3. ***What preferences regarding funeral arrangements have been set out?***
4. ***What arrangements regarding personal belongings etc. are in place?***

Date:

Signed:

Sample End of Life Plan

End of life planning for ____

Date Plan Developed: *Jan 10th 2015*
Date Plan Reviewed:
Who participated in the development of this plan?

A Circle of Support meeting was held to discuss this issue on the above date. In attendance were______ brother, Mr XXX, his sister Mrs XXX, the Named Staff, the Manager of the Group Home and the Social Worker.

Due to the number of health issues arising for _______over the last number of years it was considered necessary to put some time and thought into end of life planning on _______ behalf.

_________'s own view about death and dying

- At this point he is not able to engage in a conversation about death and dying.

_________family's thoughts with regard to _________s ***death***

- During discussion with ________ family, their preference is that for as long as he will remain in the group home where he has lived for the past 20 years. All agreed that s would be dictated by his health presentation at this time and it was agreed that any decision for ________ to leave to be supported in a medical environment would be a joint discussion between themselves, ourselves and medical supports.

- In the event of ________'s passing, their family have made it known that when this event happens they would like ________ to remain in his home and to repose there.

- Family were reassured that this was something that we also would support as being appropriate and important for ________ who has spent 20 years residing in the group home. Staff also expressed their wish to take care of _______ on his final journey.

Final Resting Place

- ______'s brother informed us that __________ would be laid to rest with his parents, who have made provision for this in their will. His final resting place would be outside XXXX where the family originate from.

This plan will be amended and reviewed in accordance with any additional information or wishes or a change in ________'s current health, which at this point is very well.

Date: __________________ ***Signed:*** ____________________________

References

Assessment and treatment of pain and other physical/psychosocial and spiritual problems (*WHO, Innovative care for chronic diseases, 2002)*

How to Break Bad News to People with Intellectual Disabilities *(Tuffrey-Wifne, I.) 2013*

Living and Dying with Dignity
The Best Practice Guide to end-of-life care for people with a learning disability. Mencap. *(Read, S. and Morris, H.,) 2008*

Care of Dying Adults in the last days of life, NICE guidelines [NG31] Published date: December 2015; https://www.nice.org.uk/guidance/ng31

Policy and Procedure Feedback Form

A Policy and Procedure Feedback Form is available on the Western Care Association Intranet (under Procedures) which will provide an opportunity to comment on any policy/procedure.
Your comments will be forwarded to the person who has the lead for the on-going development of the policy/procedure.
All comments will be collated by the person responsible and will inform the three-yearly review cycle for updating procedures.