Supporting People in Communities
St Patrick's Centre

ST. PATRICK'S CENTRE
KILKENNY

POLICY TITLE: End of Life Policy

Prepared by: Geri Wilson, Social Worker	Approval Date: 02.06.2020	Review Date: 02.06.2022
Policy Number 01 – Other Policies	Approval By Signed: ____________ CEO (Interim) Signed: ____________ Board Member	

Mission Statement

To enable people to live a good life, in their own home, with supports and opportunities to become active, valued and inclusive members of their local communities.

To enable a supported, self-directed living (SSDL) model of provision which is underpinned by our beliefs, values and vision.

Review Date:	Amendments Required	New Revision Status
02.06.2020	Policy updated	02.06.2022
Reviewed By: Geri Wilson	Approved By: Signed: ____________ CEO (Interim)	

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1.0 Introduction

1.1. The purpose of this Policy is to provide clear guidelines for all employees of St. Patrick’s Centre, Kilkenny (SPC) when supporting a person we support approaching the end of their life.

1.2. People approaching the end of their life need high quality, accessible care if they are to make genuine choices about how they are cared for and where they wish to die. Competent and compassionate care is also critical to giving people the opportunity to have a dignified death, and includes offering families, friends, staff and other persons supported bereavement support following a death.

1.3. This care should be of the same high quality regardless of diagnosis and of whether the care is carried out at home, in hospital, in the community or in any other setting.

1.4. It is intended that this policy will support practitioners and staff in SPC to develop their awareness and understanding of the End of Life Plan and how it relates to people they support.

2.0 Scope of the Policy

2.1. This policy relates to all staff, including agency staff, clinicians and anyone involved in the provision of services in SPC.

2.2. This Policy should be read in conjunction with:-

- HSE Guidance on End of Life Care in social care-led disability residential centres during COVID-19 Version 1.0 28/04/2020
- Advanced Care Guidelines
- Assisted decision making capacity act 2015
- SPC Capacity & Consent Policy 2020

3.0 Core Principles

3.1. Core principles for delivery of end of life care:

- Care is person-centred and integrated,
- Persons supported are treated with dignity and respect,
- Persons supported preferences are given due consideration.
- Care is provided after death.

3.2. People with intellectual disabilities have the same palliative care needs as others in society but may have additional needs because of their intellectual disabilities.

3.3. People with intellectual disabilities should be treated as unique individuals and efforts should be made to identify their specific experiences, needs, preferences and those who are important to them when planning for their end of life care.

3.4. Identifying when people are approaching the end of their life can be very complex, particularly in the case of people with severe intellectual disabilities. The late presentation of serious illness and limited verbal communication can exacerbate this.

3.5. To ensure that people with intellectual disabilities get the best end of life care possible it is important to develop partnerships across all settings with both formal and family supports carers.

3.6. One of the key challenges for staff and family members is how to develop sensitive, open conversations with people with intellectual disabilities who are nearing the end of life. These conversations need to take account of the persons supported preferred communication style, their cognitive abilities, their understanding of language, serious illness, death and dying as well as their concept of time.

3.7. Staff should also be aware of the Assisted Decision Making (Capacity) Act and the presumption of capacity unless otherwise proven.

4.0 Assessment, Care Planning and Review

4.1. All decisions regarding a person’s supported treatment at end of life are completed in a team approach led by the person’s GP or lead medical Consultant. All clinical decisions are made by the lead medical professional who will take into consideration the wishes of the person and the person’s family, representative and/or advocate where relevant. (HSE Guidance on End of Life Care in social care-led disability residential centres during COVID-19 Version 1.0 28/04/2020)

4.2. A timely assessment of the person’s supported needs and wishes is essential in order to establish their will and preference, taking into account the physical, emotional, social, cultural and where relevant environmental needs of the individual.

4.3. Each person supported should have an End of Life plan where relevant. This should include details of an up to date DNAR directive where relevant and all support staff should be aware of the DNAR and their responsibilities in relation to this? (National Consent Policy Part 4)

5.0 Issues to consider during end of life care planning

- How do you identify when a person supported is approaching the end of their life?
- Does the person supported have a communication passport?
- Does it contain details of the person's supported communication preferences?
- Where the person supported does not have the capacity for advance care planning does the service provider have an agreement about who should initiate or take responsibility for ensuring conversations about end of life are held?
- Who has been designated to make decisions for the person?
- Has this been agreed with the service provider?
- Does the service provider have appropriate accessible resources (e.g., pictorial/visual information to ensure that meaningful conversations can take place?

5.1. It is important to take into account the environment in which these conversations should be held. For example, for some persons supported who also have an autistic spectrum disorder, environments which are noisy, very bright or have strong smells associated with them may initiate a sensory overload which can impede their ability to understand the information being imparted.

5.2. Records of expressed end of life care wishes should be completed in accessible formats to be kept in an agreed place (e.g. within the person's supported bedroom). Ensure all staff and other key people (e.g. family members are aware of the location).

- Does your care plan assessment take into account all aspects of end of life care (social, emotional and spiritual) as well as physical?
- What is appropriate for the person supported?
- What is important to them?
- What are their values and beliefs?
- What were their previous interests, hobbies etc.?
- What support might the service provider require, i.e. health, social or palliative care services to enable them to provide appropriate end of life care for the person supported e.g. training in knowledge of intellectual disability, or education regarding the importance of non-verbal communication or in the use of DisDAT)?
- How will the person's physical and emotional distress be assessed and recorded; e.g. 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?
- Is there a Treatment Plan/ Pain Management plan?

- Are all those involved in the assessment and delivery of care confident of their ability to understand and meet the needs of a person with an intellectual disability throughout the progression of their illness?
- Is there adequate support for all those (both family and professional carers) to carry out their roles?
- Are there identified sources of training and/or supervision for the whole extended team on this?
- Has the person's supported 'circle of support' been identified and are the roles of all those involved clear?

6.0 Co-ordination of Care

6.1. Once an End of Life Care Plan has been agreed it is important that all the services identified as being required are effectively coordinated.

6.2. It is essential to establish efficient lines of communication and sharing of relevant information across the services involved.

6.3. As the person's supported condition deteriorates there will be a 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 supported. This means that at times it will be most appropriate for this to be a member of the person's supported staff but at others (perhaps in the later stages of an illness), for a member of palliative care staff to take on this role.

6.4. **Issues to consider**

- Is there a communication system in place to keep everyone involved in the care of the person supported informed of the evolving end of life care plan?
- Has a key worker been identified for the person so that there is a lead person not only for the co-ordination of all services and care but who also has a responsibility for keeping family carers and friends up-to-date with the emerging situation in keeping with the person's wishes?
- Are systems in place for services to respond rapidly and appropriately (out- of-hours as well as during working hours) to changes in circumstances as end of life approaches (e.g., changes in medication or equipment)?
- Are these services aware that the person has an intellectual disability and of any specific needs (e.g., regarding communication) which they have as a result?
- Where there are issues related to mental capacity and decision making, is there an established best interest process which is reviewed regularly and which takes into account both the person's wishes and the wishes of those closest to them?

7.0 Discussions as end of life approaches

7.1. A speech and language therapist, psychologist or other dedicated member of staff should be deployed to facilitate the expression of the person's supported end of life care preferences at whatever level they are able to express them.

7.2. Staff or family members close to the person supported may find it too distressing to talk to the person about their illness; palliative care staff may be well placed to do this but may not have the requisite communication skills. Therefore, good partnerships need to be forged to support the person supported at all stages of their illness and dying. Consideration may be given to engaging the services of an independent advocate to assist the person supported to express their will and preference.

8.0 Care after death

8.1. Good end of life care does not end at death, and all staff need to follow good practice in respect of the wishes of the deceased person's family and friends.

8.2. 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 persons supported.

8.3. When the person who has died is a person with an intellectual 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 intellectual 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.

8.4. Where those who are left behind include people with an intellectual 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.

8.5. Opportunities to acknowledge the death and to pay respect to the deceased are likely to be as important for other persons who have an intellectual disability as for those who do not have an intellectual disability. However, these may need to be adapted to the level of understanding of those taking part. Within a comfortable environment, staff should facilitate the safe expression of other persons' supported questions.

8.6. Whilst it is a normal inclination for family members to 'protect' their 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. It is important to assist family members to understand that the relationships between persons supported may have been very strong and might actually have been developed over significant periods of time in various service settings. 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 person supported.

8.7. In some families the intellectual disability may have impacted on the emotional attachment of family members. Consequently, there may be issues of guilt, anger and regret which may potentially complicate the grief of those family members left behind. It is vital not to express judgemental thoughts or behaviours which may be based on incomplete understandings of the family and which could exacerbate the distress of the family.

9.0 Immediate steps to take following death

9.1. Senior staff on duty to contact person's supported GP immediately

9.2. If next of kin are not present when person supported dies they should be informed as soon as possible by the manager or senior member of staff on duty.

9.3. The deceased person is to be treated at all times with the upmost respect and in a dignified manner.

9.4. The person's supported privacy is to be maintained and protected. Where indicated in the person's supported End of Life Care Plan relevant religious or spiritual representatives should be contacted.

9.5. Support and advice should be provided, by the manager or senior member of staff on duty; in relation to funeral arrangements which should be outlined in End of Life Care Plan.

10.00 Steps to be taken by SPC in weeks following death

- Social work department to liaise with staff in deceased person's house to organise the delivery of the person's personal effects to family at a time agreed with the family.

- Social work department to continue to offer support to the deceased person's family. And information about bereavement services to be provided if appropriate.

- Social work department to request copy of death certificate from family for SPC records.

- Social work dept. to liaise with SPC finance dept. to ensure that all financial matters are dealt with, i.e. probate, bank accounts, outstanding invoices etc.

Note: If the person's supported death is due to Covid 19 related illness the SPC guidelines in relation to Covid 19 will be immediately implemented.

10.00 References

- National end of Life Care Planning NHS
- HSE Guidance on End of Life Care in social care-led disability residential centres during COVID-19
- Version 1.0   28/04/2020
- National Consent Policy (2019)
- SPC Advanced End of life Guidelines April 2014
- Assisted Decision Making (Capacity) Act 2015