Saint John of God Kerry Services

Hospitality - Compassion - Respect

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End of Life Care
Policy and Procedure

Saint John of God Kerry Services

Title:	End of Life Care
Document Reference:	Kerry
Revision Date:	May 2023
Revision Number:	04
Pages, incl. cover & signature:	24
Approved By:	PPP Group

Policy and Procedure

Introduction

End of life care is the term used to describe care that is provided during the period when death appears to be imminent, and life expectancy appears to be limited.

1. Purpose

To provide clear direction to staff of Saint John of God Kerry Services in relation to end of life care, preserving life, allowing a natural death at the end stage of a terminal illness (where this has been discussed, agreed and documented in advance by a registered medical practitioner), and in the instance of a documented advance directive by the resident/family representative not to administer CPR.

2. Aims

The aim of this policy and procedure is:

- To support the end-of-life needs of adults with an intellectual disability and their families through holistic assessment in conjunction with the individuals GP, (Palliative care team, and relevant multidisciplinary team/primary care teams.)
- To ensure all staff are aware and knowledgeable in relation to this document and have the ability to communicate it precisely in dealings with GPs and the residents' families / carers / advocates / meaningful others.

3. Scope

This Policy applies to all of Saint John of God Kerry Services staff.

4. Legislation/other related policies

- Assisted Decision Making (Capacity Bill) 2015
- Health Information and Quality Authority (2013), National Standards for Residential Services for Adults with Disabilities

- Health Act (2007) Care and Support of residents in designated centred for persons (Children and adults with disabilities) Regulations 2013
- Guidance on end-of-life care 2010 (St Anne's C.N.U. Galway)
- Palliative Care Needs Assessment, HSE National Clinical Programme for Palliative Care Clinical Strategy and Programmes Directorate (2014)
- Palliative Care Competence Framework Health Service Executive (2014)

5. Roles and Responsibilities

5.1 Programme Manager/Person in Charge

- It is the responsibility of the Programme Manager or their nominated representative to ensure that this policy and procedure is available to all staff involved in the provision of end-of-life care within Intellectual Disability services in their service provision.
- It is the responsibility of the Programme Manager to support staff to attend any relevant end-of-life education, training and development in so far as is practicable.

5.2 Responsibility of the Unit/Centre Manager

- It is the responsibility of the Unit/Centre manager to communicate with the individuals contact person/family member or other person(s) nominated in the event of death, or any other life threatening situation, in a timely manner.
- It is the responsibility of the Unit/Centre manager to monitor the skill level of staff within their area of responsibility and to ensure that they have the opportunity to develop their skills/knowledge where a deficit is identified.
- The Unit/Centre manager is responsible for ensuring confidentiality is maintained.
- It is the responsibility of the Unit Manager to arrange MDT meetings to include the General Practitioner.

5.3 All staff

- All staff have a responsibility to work together to ensure that there is an integrated person centred comprehensive approach to the care of each individual at end of life.
- It is the responsibility of individual staff to read this document and having satisfied themselves that they understand its content and

sign to that effect on the policy and procedure acknowledgement form.

- It is the responsibility of individual staff members involved in supporting individuals with their end-of-life care to do so in an appropriate, safe manner at all times and to be personally responsible for ensuring that their actions comply with this policy and procedure.
- All staff working with persons with an intellectual disability are required to understand and recognise the common trajectories of life limiting conditions (Palliative Care Competence Framework Steering Group 2014).
- End-of-life care provision is the responsibility of ***all*** staff of the care team and a palliative care approach should be a core skill of all health and social care professionals.
- It is the responsibility of individual staff members to alert their line manager if they have a competency development need in relation to the provision of appropriate end-of-life care and work to develop their competence in that area. Identify Training Requirements.
- It is the responsibility of individual staff members to ensure that the individual and his/her family are cared for with dignity and respect and supported through effective, open and sensitive communication.
- All Staff are responsible for the assessment, planning, implementation and evaluation of appropriate End of Life care.
- All staff have a responsibility to carry out the care identified in the person's end-of-life care plan.
- It is the responsibility of individual staff members to update their knowledge regarding palliative care principles and approaches in order to competently and comprehensively care for each individual at all stages of a life limiting illness including end of life care.

- The persons key worker is responsible for ensuring that the following are documented:
    1. A record of the individuals specific end-of-life wishes
    2. Current contact details of family members and significant others
    3. Record individuals religion, and contact details of minister of faith, or Humanistic Counsellor

6. End of Life Care Plan

End of life care is the term used to describe care that is provided during the period when death appears to be imminent and life expectancy appears to be limited to a short number of hours or days (HSE, 2014).

6.1 Goals to achieve person centred end-of-life care include:

- Recognising that the person is dying;
- The promotion of quality of life, dignity and respect at end-of-life for the person and their family;
- The promotion of physical, psychological, social and spiritual wellbeing and address symptoms that arise, to ensure comfort and safety as directed by GP /palliative care Team.
- To ensure appropriate bereavement support is made available to the person and their family and friends.
- Contact palliative Team as required

7. Guidance for the development of a Person Centred End of Life Plan

(Each area requires the development of an individual plan of care, see appendix 2)

7.1 Person Centred Communication
• Ensure clear, sensitive communication and discuss with the Resident and their family; • Their wishes in relation to care; • Their preferred place of care; • Spiritual, religious & cultural needs http://www.hse.ie/eng/services/Publications/SocialInclusion/InterculturalGuide/interculturalguide.pdf • Aspects of care relating to treatment, safety and support; • Involvement of multidisciplinary team e.g. Specialist Palliative Care team, Social Worker, Pastoral Care, and Psychologist as appropriate.

7.2 Management of Physical Symptom Management/Comfort Measures
The aim of Symptom Management/Comfort Measures is to relieve any symptoms that may cause discomfort or distress by: • On-going *assessment* using appropriate assessments tools; • On-going *management and evaluation*;

- On-going *sensitive communication* with the person and his/her family to clarify symptoms and agree treatment/comfort options;
- Observing for signs and symptoms of discomfort which may include some/any of the following:
    - Pain: somatic, visceral, neuropathic
    - Neurological: depression, anxiety, agitation, confusion, delirium, seizure
    - Gastrointestinal: nausea, vomiting, constipation, anorexia
    - Respiratory: dyspnoea, breathlessness, cough, increased
    - Respiratory secretions
    - Fatigue disproportionate to level of activity or not relieved by rest
    - Other: Level of consciousness, mobility challenges, oedema, wound problems
    - *(this list is not exhaustive)*

- Implementing and reviewing appropriate supports including pharmacological, physical, psychological and complementary therapy;
- Ensuring appropriate delivery and monitoring of comfort measures including enteral/oral intake, oral & eye care, skin care, bowel management;
- Regular evaluation of symptoms and accurate documentation;
- Where symptoms are severe or intractable discuss with the persons GP and where appropriate Specialist Palliative Care Team;
- Review the use of any non-essential treatment/medication in conjunction with the person's medical team.

7.3 Psychological, Social and Spiritual

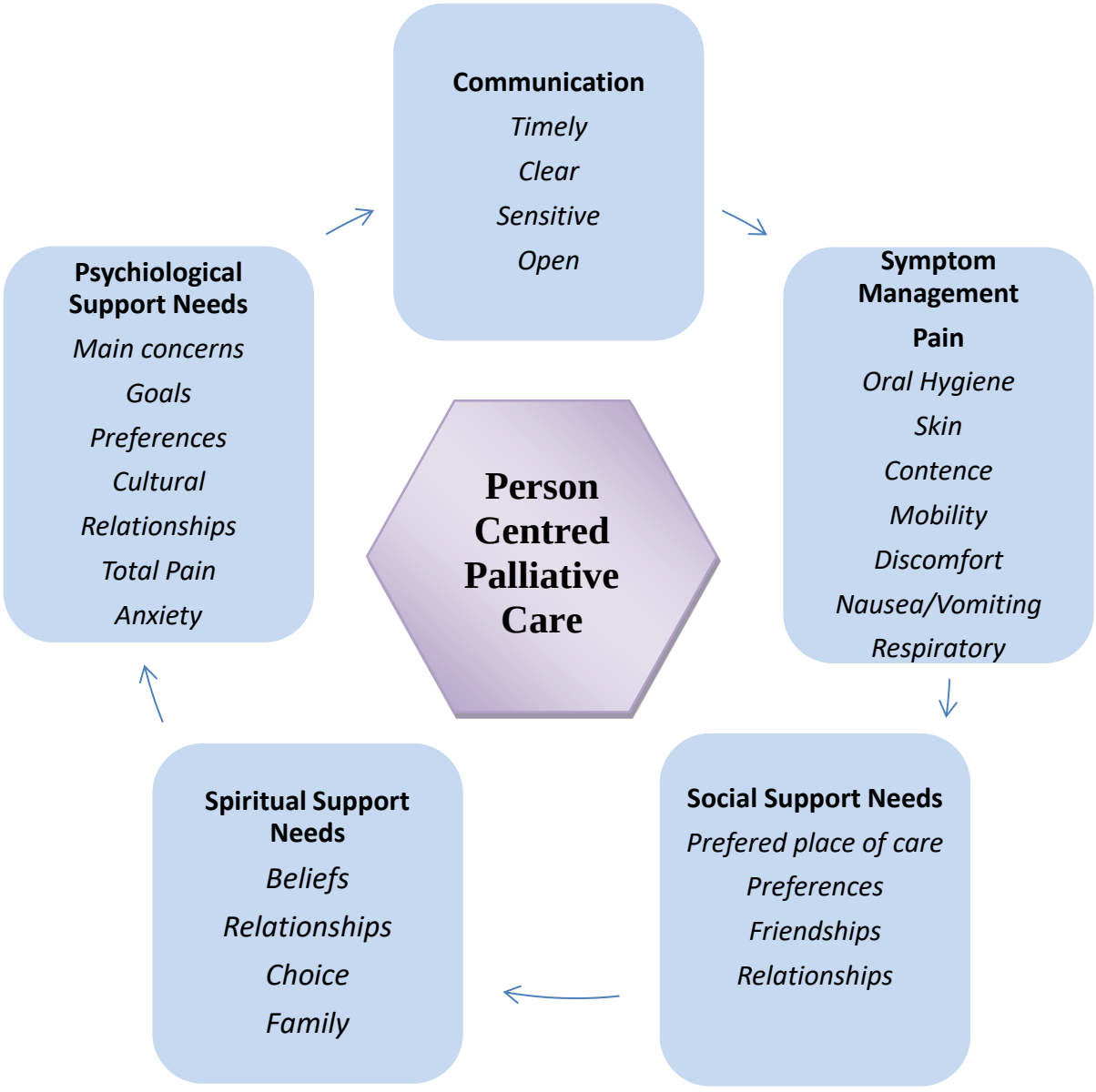
- Provide an opportunity for the person to express their emotional needs and concerns and what provides them with strength and comfort;
- Ensure open, sensitive communication that is empathetic, non-judgemental and appropriate to the communication level and preferred method of communication used by the individual;
- Address issues relating to total pain;
  Total pain is uncontrolled, multidimensional pain associated with psychological, spiritual pain that may contribute to physical symptoms (HSE 2014 b)
- Psychological distress that may be acerbated by an existing mental health issue;
- Provide access and an appropriate environment for the person and family that ensures dignity and privacy;

- Ensure spiritual & religious needs are addressed in an individualistic manner before and after death. Explore with the person and their support team if their spiritual/religious beliefs offer comfort
- Discuss with the team how the persons expressed emotional and/or spiritual needs can be met by the team.

7.4 Following death

- Ensure staff member records time of death if GP not present;
- Remove all medical equipment
- All staff to refer to the guidelines (appendix 1) on care of the deceased person after death
- Contact the individuals GP or out of Hours GP Service (South Doc 1850 335 999) to attend and confirm the death of the Resident and discuss arrangements for contacting the Coroner .
- Facilitate and support family to spend time with their relative following death;
- Support family in contacting relatives and making initial arrangements;
- Prepare the person in keeping with family and cultural wishes.
- Co-ordinate and assist with transfer of the Resident to the funeral home/mortuary according to Resident and family Choice
- Notify HIQA as per HIQA Guidelines (Notifiable Events).
- Contact palliative care to inform them of the death and to arrange the collection of any appropriate medical devices.
- Notify as per Governance Structure the Person on call for Saint John of God Kerry Services

Figure 1.0


Communication
Timely
Clear
Sensitive
Open
Symptom Management
Pain
Oral Hygiene
Skin
Contence
Mobility
Discomfort
Nausea/Vomiting
Respiratory
Social Support Needs
Prefered place of care
Preferences
Friendships
Relationships
Spiritual Support Needs
Beliefs
Relationships
Choice
Family
Psychiological Support Needs
Main concerns
Goals
Preferences
Cultural
Relationships
Total Pain
Anxiety
Person Centred Palliative Care

8. References

Health Act (2007) Care and Support of residents in designated centred for persons (Children and adults with disabilities) Regulations 2013.

Health Information and Quality Authority (2013), National Standards for Residential Services for Adults with Disabilities, Dublin: HIQA.

Health Service Executive (2014) Glossary of Terms, 2nd ed. National Clinical Care Programme for Palliative Care, Clinical Strategy and Programmes Directorate, Dublin: Health Service Executive.

Health Service Executive (2013) Guidance on end of life care, St Anne's Community Nursing Unit, Galway: HSE.

Health Service Executive (2010) Minimum Data Set, Dublin: Health Service Executive.

Health Service Executive (2014 b) Palliative Care Needs Assessment Guidance, National Clinical Care Programme for Palliative Care, Clinical Strategy and Programmes Directorate, Dublin: Health Service Executive,
Available on: www.hse.ie/palliativecareprogramme
http://hospicefoundation.ie/what-we-do/palliative-care-for-all/

Palliative Care Competence Framework Steering Group (2014), Palliative Care Competence Framework, Dublin: Health Service Executive, Available on: http://aiihpc.org/upload/education/files/1342606786_Palliative_Care_Competence_Framework_Report_R1.pdf

www.hse.ie/palliativecareprogramme

Appendix 1

Guidelines on Preparing the Deceased.

- It is the responsibility of all staff to respect the privacy, dignity and security of the deceased.
- Providing appropriate privacy for the bereaved to view the deceased.
- Allowing time for relatives to spend with the deceased (this may depend on whether there are medico legal objectives or infection control risks which may restrict access)

Preparing the deceased for viewing.

- Position the body in alignment, but consider religious beliefs.
- The body, needs to be cleansed
- Close eyes by applying light pressure/ use cotton wool eye pads dampened).
- Consider placing a small padding under the chin to support mouth closure.
- Ensure that the face is visible and that bedcovers are secured to neck/chin level.

Preparing the environment for viewing.

- Where possible provide a private room for viewing.
- Provide seating
- Remove medical equipment
- Change sheets and replace with clean bedding
- Ensure bedside area is tidy
- Ensure that residents nearby receive appropriate support and communication about what is happening
- Consider placing a photograph of the deceased on bedside locker.

Preparing the family for viewing of their relative.

- Ensure sensitive communication of what to expect and what the deceased will look like.

- Ensure privacy that staff remain available for the family.

- Ask relatives whether they would like a spiritual leader to be present to perform a blessing or perform other appropriate ceremonies.

- Give relatives adequate time to spend their last moments with the deceased.

Appendix 2

Accessible Planning Tool

Glancing Back Planning Forward

About this guide

This is information to help you prepare for the future

This information will help you to make decisions so your friends, family and staff will understand your wishes

Sometimes you make decisions that are easy like what you would like to eat

Sometimes you make decisions that are difficult like what will I do if I get very sick

By planning ahead you will know who will help you and they will know what you wa

Accessible Planning Tool

Glancing Back Planning Forward

About this tool

This is a planning tool to help you let everyone know what you want if you get very sick and will not get better

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It can be filled out when you are ready to do so

You can change anything you write in the tool any time you want

The tool

Personal Details

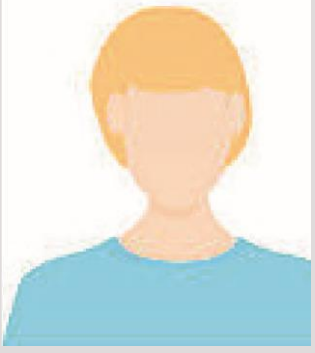
My name is

Insert your photo here

I live in

My Carer is

Picture(s) of carer
My parent/sister/
brother/key worker



Accessible Planning Tool

Glancing Back Planning Forward

The tool

Tell us what you want to do

If you were sick how much information would you like to know about sickness?

☐ None ☐ A little ☐ A lot

If the doctor had to tell you news about your health who would you like to be with you

Name of the person

His/her phone number

If you were very sick and the doctor said you would not get better where would you like to be cared for?

Put 1 beside your first choice
Put 2 beside your second choice
Put 3 beside your third choice
Put 4 beside your fourth choice

☐ At home
☐ In Hospital
☐ In a Hospice
☐ In a Nursing Home

Accessible Planning Tool

Glancing Back Planning Forward

The tool

Tell us what you want to do

If you were very sick is there someone from your church or religious group you would like to tell

Priest/Minister/Other [Name and details]
Do not have a religious preference

Phone number

Think and answer when you are ready

The next questions are about if you got very sick and you would not get better

Are there any things you would like in your last days of your life?

Some of these things might be:

- People you would like to see
- Places you would like to go
- Being kept comfortable
- Doing everything the doctor or nurse can think of to make you feel better

Accessible Planning Tool

Glancing Back Planning Forward

The tool

Are there any things you would NOT like to do in the last days of your life?

Some of these things might be:

- Going into hospital
- Doctors or nurses doing things that might be painful

Are there any things you would like to do if you were able to?

Is there any person you would like to see or talk to? Please write their name(s) and phone number(s).

Would you like to be in a quiet place or a place with activity around?

Would you like lots of visitors or just a few close friends?

Accessible Planning Tool

Glancing Back Planning Forward

The tool

Think and answer when you are ready

Questions about when you die

Would you like to make a will?

☐ Yes ☐ No

After you die are there any particular people that you would like to be told about your death?

Accessible Planning Tool

Glancing Back Planning Forward

The tool

After you die are there any clubs or groups that you would like to be told about your death?

[name and details]

None ☐

Tell me the name of the person who you would like to make your funeral arrangements

[name and details]

I don't mind ☐

Would you like to be buried or cremated?

☐ Buried

☐ Cremated

Accessible Planning Tool

Glancing Back Planning Forward

The tool

Where would you like to be buried?
Check with family or service re plot

[name place and details]

Where would you like to have your ashes placed
Check with family or service re plot

[name place and details]

Is there a particular celebrant you would like to do your funeral?

Please list anything else you would like in your funeral service or ceremony such as a favourite piece of music or poem?

Accessible Planning Tool

Glancing Back Planning Forward

End of Life Planner Checklist

I have thought about the things I want to happen at the end of my life ☐

I have thought about the care I want to receive at the end of my life ☐

I have talked about these things with people I trust ☐

I have filled out this form with someone I trust ☐

I am happy with the plans I have made on this form ☐

Signed:

My signature: _____

The signature of the person supporting me : _____

Relationship of this person to me (e.g., family, friend, keyworker):

_____

Date: _____

Review

I have reviewed this document with someone I trust ☐

I am happy with changes I have made to this document ☐

Signed:

My signature: _____

The signature of the person supporting me: _____

Date: _____

Unit Head Sign:

Date Discussed with Circle of Support:

Date:

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

HEALTHY HAPPY AGEING

AIIHPC
All Ireland Institute of Hospice and Palliative Care

Pleases also click on the following to access the carers guide:
https://www.tcd.ie/tcaid/accessibleinformation/carersguide.pdf

SIGNATURE PAGE

I have read, understand and agree to adhere to the attached Policy and Procedure:

Print Name	**Signature**	**Area of Work**	**Date**