Kerry Parents & Friends Association

Guidelines on

End of Life Care Planning

(Death & Dying)

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KERRY PARENTS & FRIENDS ASSOCIATION

Guidelines on Death and Dying

1.0 Introduction

It is the fundamental right of every human being to receive good quality end of life care that is individualised, promotes quality of life, and is totally respectful of the dying person's physical, emotional and spiritual needs.

2.0 Purpose of these guidelines

Is to give structure, direction and support to staff supporting the individual at end of life.

3.0 Scope

These guidelines apply to all Kerry Parents and Friends staff who support end of life care.

4.0 Roles & Responsibilities

4.1 Senior Management Team must ensure these guidelines are adhered to.

4.2 Person in Charge / Manager must ensure that all staff within their team:

- ✓ Are provided the opportunity to read the guidelines
- ✓ Have the opportunity to discuss and clarify any queries they have on the guidelines contents
- ✓ Sign to indicate they have read and understood the guidelines with a copy of signatures held locally
- ✓ Adhere to and implement the guidelines within the designated area
- ✓ Ensure all relevant parties are aware of a DNAR decision support form or Advance Health Care directive (*Irish hospice foundation)* if in place

4.3 Frontline Staff must ensure they:

- ✓ Are familiar with, and adhere to the content of these guidelines.
- ✓ Sign to indicate that they have read and understood the guidelines

5.0 What are the principles of high quality End-of-life Care Planning

The Irish Hospice Foundation defines End-of-life care planning as "…person-centred and involves finding out the wishes and preferences of the person regarding what they want for their end-of-life care. It is built around the needs of the individual, with the *person* always at the heart of every decision. It is a holistic approach to care that responds to the person's physical, social, spiritual and psychological/*emotional* needs"

The general principals of high quality end of life care planning are

1. **Ethical Decision Making**
    - ✓ Persons with intellectual disability have the same rights as all persons, e.g. the right to life, autonomy, dignity, bodily integrity, freedom from inhuman and degrading treatment as well as the right to information, to consent and to confidentiality.

2. **Person-Centred Approach**
    - ✓ Focus on the experience of the person receiving the care & on what matters most to them
    - ✓ Be attuned to the way in which people make sense or meaning out of the world
    - ✓ Help the person to express themselves
    - ✓ Enable & foster relationships that are important to the person
    - ✓ Recognise & meet the needs of those in a person's circle of support

3. **Informed Decision-Making:**
    - ✓ Each individual should be supported to make informed decisions about what they would like to happen at the end of life.
    - ✓ This should include informed decisions on their future healthcare, where goals and preferences are identified. This involves providing information about potential medical interventions, likely outcomes, and the implications of different choices.
    - ✓ These discussions should include those identified in a person's circle of support & those within their multi-disciplinary team to ensure a clear understanding of the person's wishes.

4. **Consent**: All adults supported within our service have a fundamental ethical and legal right to control their own lives, to make informed decisions on matters that relate to them and to decide what happens to their own bodies. It is therefore essential that valid consent is obtained for health and social care interventions.

5. **Advocacy**: All staff working supporting a person fulfils the role of an advocate. This role includes
   - ✓ Getting to know the person and supporting them to have their wishes, will and preference kept at the centre of all decision making
   - ✓ Presenting information to the person in ways that assist the person to make their own informed decisions and choices. (Advocates are never decision makers **for** the person)
   - ✓ Not being influenced or compromised in carrying out their role by any other party and cannot do anything the person does not want them to do.
   - ✓ Adopt a 'Will and Preference' V 'Best Interests' approach.
   - ✓ Advocacy can also be sourced from the National Advocacy Service (NAS) and through SAGE advocacy (over 65's)

6. **Communication:**
   - ✓ Open, honest and sensitive conversations through a person's preferred communication method with them about their condition and prognosis, potential medical interventions, likely outcomes and the implications of different choices is required.

7. **Cultural Sensitivity:**
   - ✓ Consideration of cultural and religious beliefs is important when planning for end of life care. All staff should be sensitive to the diverse backgrounds and values of the people being supported.

8. **Emotional needs**
   - ✓ In addition to physical symptoms, people who are at a palliative stage often experience emotional symptoms, such as anxiety, loneliness, depression and anger, which are all associated with grief.
   - ✓ Anxiety can include feelings of apprehension, fear and dread, which can lead to nausea, dizziness, shortness of breath and diarrhoea.
   - ✓ Loneliness is a 'subjective, unwelcome feeling of lack or loss of companionship or emotional attachment with other people'.1 It is often experienced in conjunction with social isolation, if the person has little social contact or others have withdrawn from them. Some people may feel alone even when in the company of others.

- ✓ Depression may result in a loss of pleasure or interest in things around them. Depressed people may feel hopeless or helpless and become isolated from those around them.
- ✓ Anger can affect the way people talk, act and accept their treatment and it is a common reaction to a life-threatening illness.
- ✓ These strategies may not solve the issue every time and we may need to call on support from experienced and senior clinicians, but often just listening to the person's concerns, displaying empathy and validation can diffuse a situation and provide the person with some sense of control in a situation that can be very disempowering.

9. Documentation

- ✓ All discussions, choices and preferences must be accurately recorded using the End of Life Care Planning Tools (appendix 1)

10. Flexibility and Review:

- ✓ All End of Life care plans should be revisited as required and if necessary, revised over time. As a person's preferences may change based on evolving health conditions, personal values and/or life circumstances.

11. Interdisciplinary Collaboration:

Interdisciplinary communication should include collaboration between KPFA staff and other healthcare professionals, including GP, consultant, nurses, palliative care, other relevant experts and formal advocacy supports through NAS and SAGE. Such an approach ensures

- ✓ That the person's wishes are known, understood and respected across different domains of care
- ✓ Ensures a person is not subjected to an unwanted, or inappropriate and harmful intervention

12. Circle of Support Involvement:

- ✓ Involving the identified people within a person's circle of support in End-of-Life Care planning is important. This can help ensure that the person's wishes and preferences are understood and supported by those who may be involved in their care.

13. Training and Education:

- ✓ Education and Training needs are identified and supported for the team as required
- ✓ Supports are available as required for all staff through the Employee Assistance Programme

6.0 End-of-Life Care Plans and Advance Healthcare Directives

The terms "end-of-life care plan" and "advance healthcare directive" refer to different aspects of end-of-life planning.

End-of-Life Care Plan:

- An end-of-life care plan is a comprehensive strategy developed for individuals who are approaching the end of their lives, often due to a life-limiting illness. The focus is on providing comfort, managing symptoms, and addressing the physical, emotional, and spiritual needs of the individual during the final stages of life.
- Components of an end-of-life care plan may include preferences for medical interventions, location of care (e.g., home, hospice, hospital), pain management, emotional and spiritual support, circle of support. The involvement, and decisions about resuscitation and life-sustaining treatments.
- The primary goal of an end-of-life care plan is to honour the individual's wishes and enhance their quality of life during its final phase.
- An End-of-life care plan **may include** an Advance Healthcare directive or an Enduring Power of Attorney

6.1 What is an Advanced Healthcare Directive

- ✓ An advance healthcare directive can be part of the broader end-of-life care planning process.
- ✓ An advance healthcare directive is a **legal** document that outlines an individual's preferences for medical treatment in case they become unable to make decisions for themselves.
- ✓ It is provided for within the Assisted Decision Making (Capacity) Act (2015) but does not require to be registered with the Decision Support Service

- ✓ In order to make an Advance Healthcare directive, you must be over 18 and must have capacity at the time.
- ✓ It is a broader concept that encompasses decisions not only related to end-of-life care but also to various medical interventions at any stage of illness or incapacitation.
- ✓ Components of an advance healthcare directive may include the designation of a healthcare proxy (someone authorized to make medical decisions on behalf of the individual).
- ✓ An advance healthcare directive is not limited to end-of-life situations; it can guide medical decisions in scenarios where the person may lose decision-making capacity temporarily or permanently
- ✓ For more information on Advance Health Care Directive consult the Decision Support Service 10922 MHC DSS Your Guide to an Advance Healthcare Directive - screen.pdf (decisionsupportservice.ie)

6.2 What is An Enduring Power of Attorney

Enduring Power of Attorney (EPA):

- An Enduring Power of Attorney can form part of End-of-Life care planning. It is a legal document that designates a trusted person (the attorney) to make decisions on behalf of the individual, in a range of personal and financial affairs.
- An EPA grants authority to the designated person (attorney) to make decisions related to property, financial affairs, and personal welfare (including healthcare decisions) on behalf of the individual. The powers granted can be broad or specific, depending on the individual's preferences.
- An Enduring Power of Attorney can be activated when the individual has capacity or in some cases, when capacity is lost. The attorney assumes decision-making authority as specified in the document.
- For more information refer to 6466-SI-Planning-Ahead-A5-web-FA2.pdf (safeguardingireland.org) & Making an enduring power of attorney | Decision Support Service

6.3 End of Life Care Planning Tools

A person-centred approach to end of life care planning acknowledges the different and individual needs of the person being supported to ensure the physical, emotional, and spiritual needs of the person are consistently in place in the event of ill health and end of life. Accordingly, KPFA have a suite of appropriate resources that can be used depending on the person's individual wishes and preferences. These resources make up what is referred to as the End of Life Care Planning tools within this guide. The components of the End of Life Care Planning Tools are available on appendix 1. These documents are available individually through sharepoint and can be used as appropriate with the individual.

End of Life Care Planning

1. Section 3.4 AON, Planning for my End of Life: KPFA
2. DNAR decision support form: KPFA (if relevant) appendix 2
3. Glancing Back Planning Forward. Accessible End of Life Tool: Trinity Centre for Aging and Intellectual Disability
4. Glancing Back Planning Forward. How to use the Accessible Planning Tool: Trinity Centre for Aging and Intellectual Disability
5. Glancing Back Planning Forward. A Guide for Carers: Trinity Centre for Aging and Intellectual Disability
6. Think Ahead. My Personal Wishes & Care Plan: Irish Hospice Foundation
7. Think Ahead. My Advance Health Care Directive: Irish Hospice Foundation
8. Think Ahead. My Medical Summary Form: Irish Hospice Foundation

Actively Dying

9. Care Plan for My End of Life: KPFA
10. DNAR decision support form: KPFA (if relevant) appendix 2

Easy Reads

11. Let's talk about Death. Down Syndrome Scotland
12. Easy Read Guidance for CPR – NHS trust

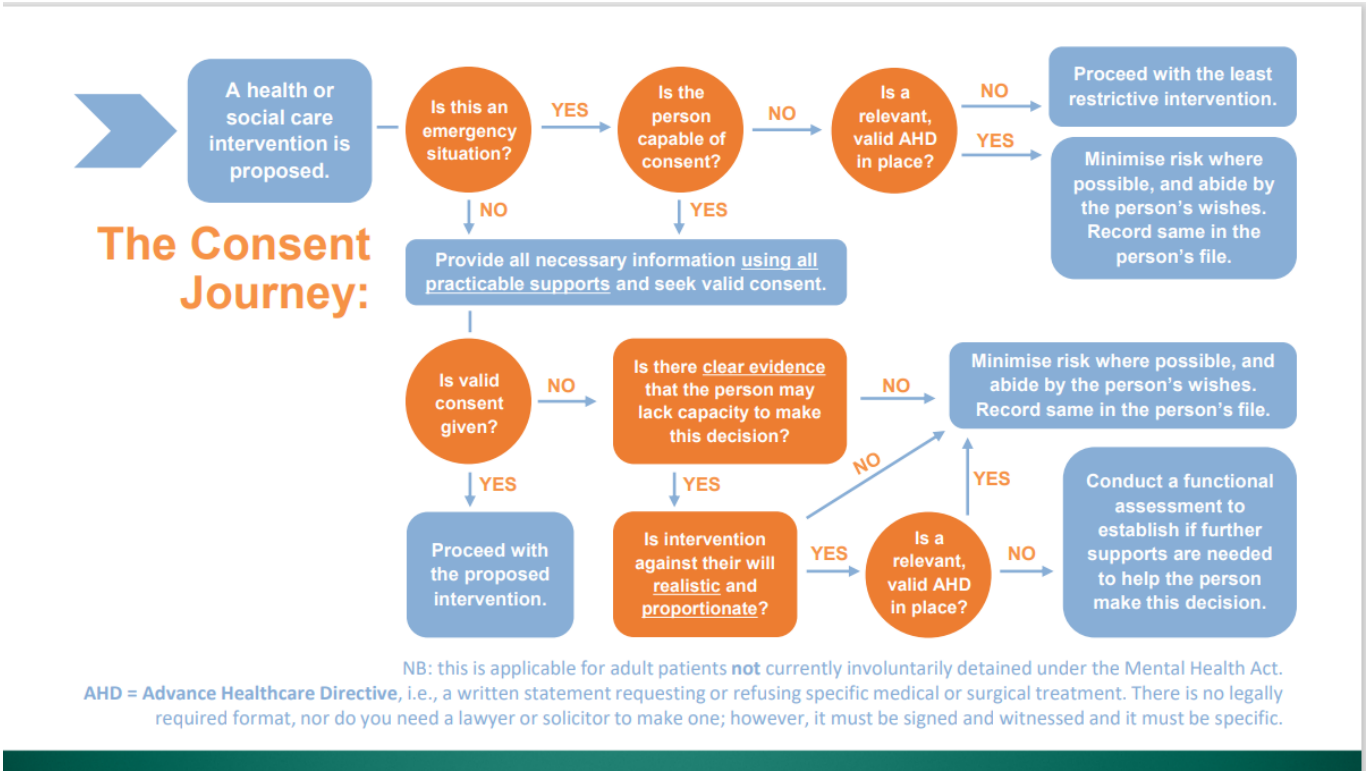
7.0 Consent

What is Consent and why is it important?

The National Consent Policy defines consent as "….. giving of permission or agreement for a treatment, investigation, receipt or use of a service or participation in research or teaching".

In order for a person to give a consent a person must be

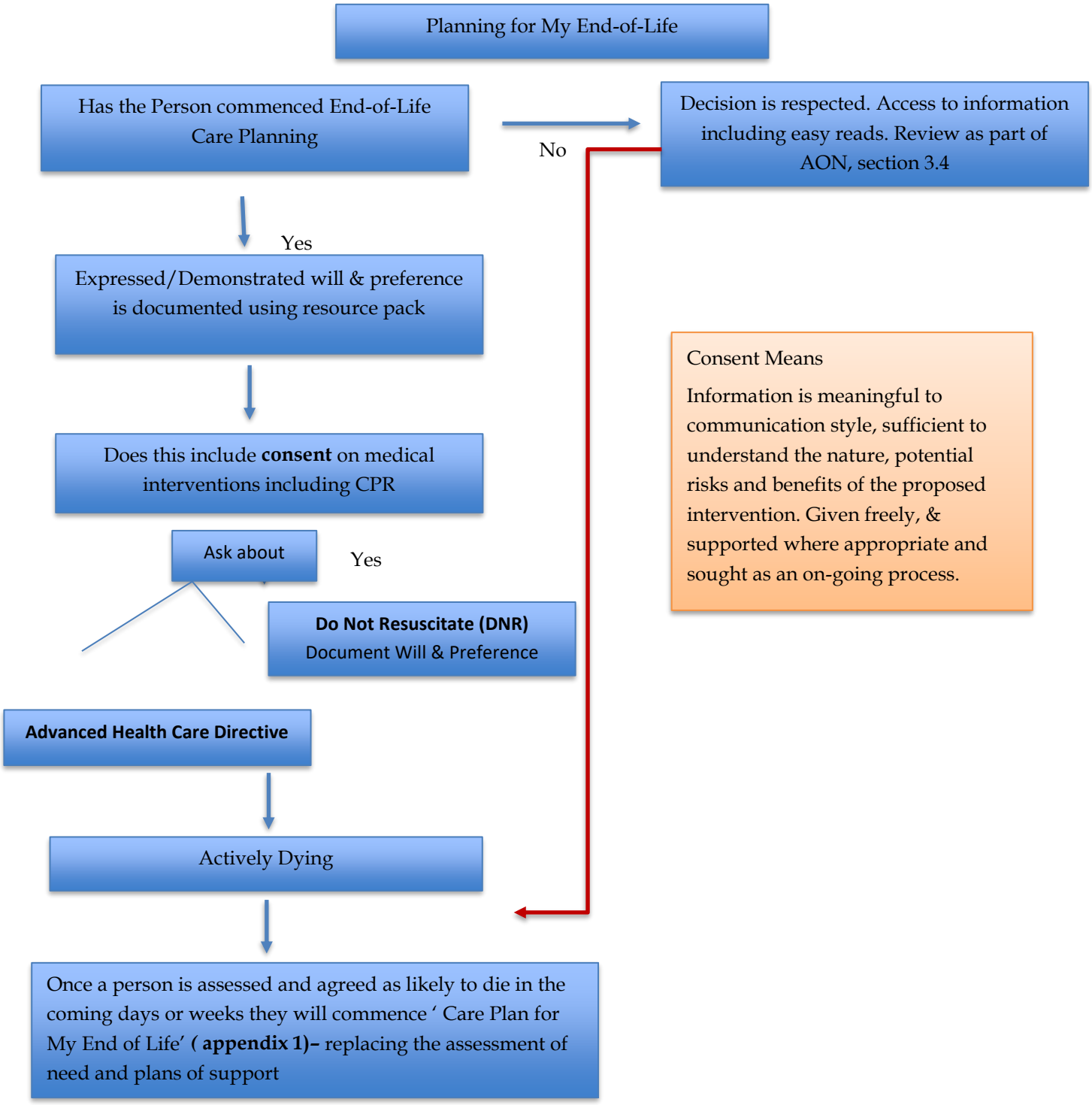
- ✓ Given information about the decision/choice in a way that they can understand
- ✓ They must be given sufficient information to be able to understand the nature, potential risks and benefits of the proposed intervention.
- ✓ Not be acting under duress; and
- ✓ Have the decision-making capacity to make the decision (even if requiring support to do so).
- ✓ Seeking consent should usually occur as an ongoing process rather than a one-off event.
- ✓ A person can withdraw consent at any time
- ✓ A person can refuse to consent, even if this is deemed unwise



Lee-Ann Scott: 2024, HSE Patient and Service User Engage

8.0 End-of-Life Care Planning: Promoting the well-being, (physical, emotional & spiritual) of the individual

KPFA recognises the important role of staff in supporting the person to make complex decisions, and involving their circle of support and multidisciplinary team to try to arrive at the most appropriate decision in collaboration with the person.



9.0 End-of-Life Care Planning: CPR & DNAR's

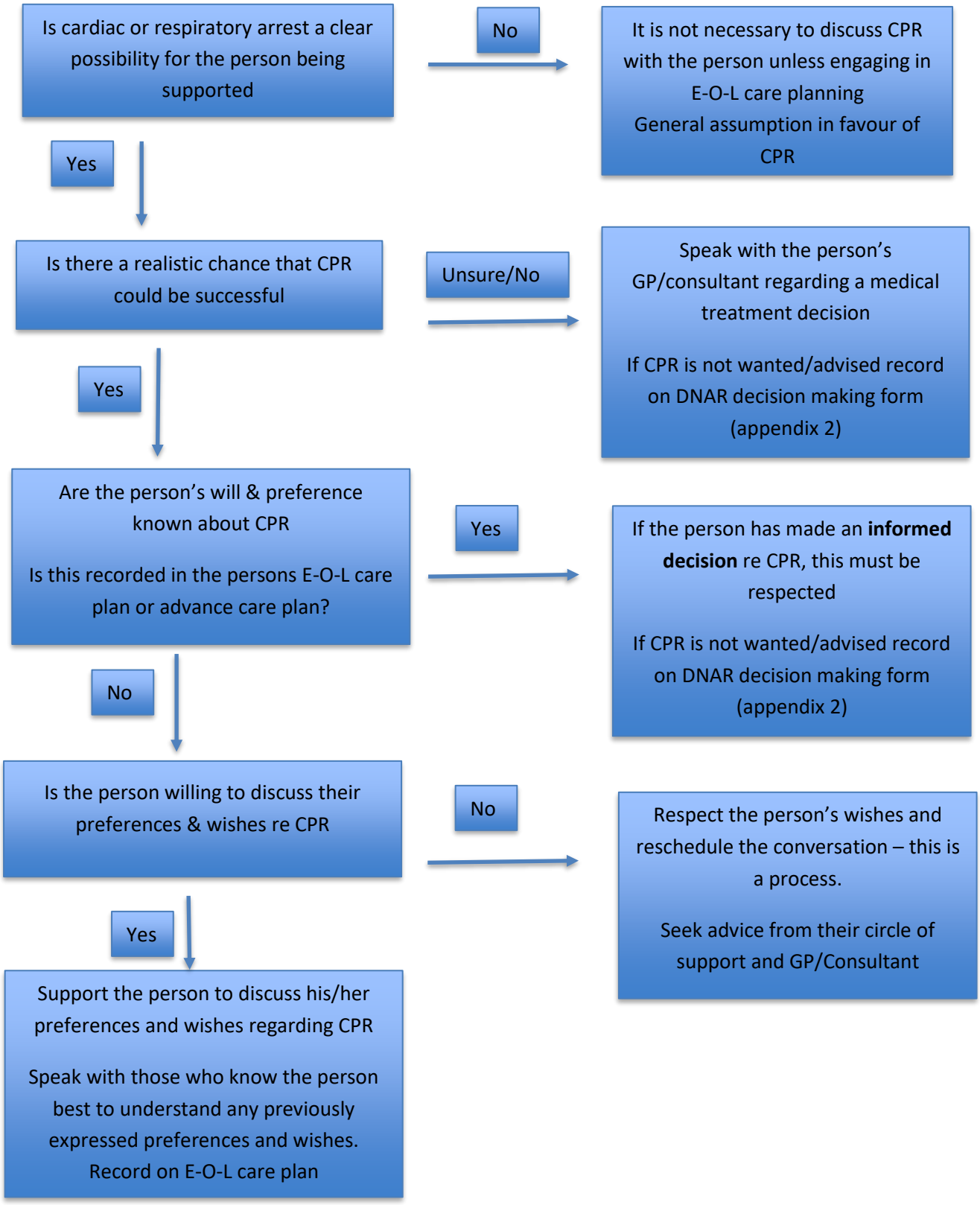
End-of-life care planning includes consideration of cardiopulmonary resuscitation CPR and Do Not Attempt Resuscitation DNAR.

CPR is an emergency life-saving procedure performed when an individual's heart has stopped beating or when they are not breathing effectively. CPR is designed to manually maintain blood circulation and provide oxygen to the body's vital organs until the emergency services arrive.

It is currently the practice of Kerry Parents and Friends Association to commence Cardio-Pulmonary Resuscitation (CPR) immediately in the case of respiratory or cardiac arrest. All health care staff in the organisation have a duty to act in the best interest of the people we support.

- ✓ All staff are trained in first aid including resuscitation
- ✓ Call 999/112 to ensure access to emergency support from ambulance service
- ✓ In the event that a person we support experiences a cardiac arrest, staff will commence CPR unless a DNAR is in place.

9.1 KPFA –Supporting Decisions around CPR



9.2 End-of-Life Care Planning: Sudden Death

All designated centres and day services must have their own emergency protocols planned for dealing with sudden death. **– template for same –** Appendices

- ✓ If the person is pronounced dead PIC/ familiar staff will inform the Family/key support person and the Director of Service
- ✓ The Doctor/ emergency services pronouncing the death will notify the Coroner when he attends . PIC/manager will clarify that this has happened. KPFA Service to record the death, detailing time and date.
- ✓ The body may not be moved without the Coroner's instruction.
- ✓ The Person in Charge on duty will notify HIQA using NF01 within 3 working days. Incident will be recorded according to Association Policy.
- ✓ If the person is for post-mortem the body is to be left intact, for example, no devices or tubes are to be removed and medications are to be retained.
- ✓ The person's belongings are to remain untouched and this is explained to next of kin as a requirement by the Coroner, until they are satisfied the deceased body can be released to the undertaker or sent to the mortuary for post mortem.
- ✓ A Garda presence may be requested by the Coroner to sit with the person's remains until removal for post mortem.
- ✓ No funeral arrangement can be made until the coroner releases the deceased remains to the requested Undertaker.

9.3 Do not attempt resuscitation DNAR

DNAR means if a person's heart or breathing stops (medical emergency) staff will not try to restart it. A DNAR is about CPR only and it **does not mean** that a person will not get other care and treatment. The person will continue to have all other appropriate care, treatment and support that they need.

Decision Making around CPR or DNAR must

- ✓ always be made on the basis of individual assessment of each individual case. It should not focus solely on age or disability, as doing so is contrary to human rights.
- ✓ takes into account the person's own goals and preferences regarding the appropriateness of CPR
- ✓ requires balancing the likelihood of benefit with that of the harm from preforming CPR in each individual case.
- ✓ CPR has poor success rates for individuals who have severe acute non-cardiac illness or those with multiple chronic illnesses or with long term illness or those approaching end of life 'ordinarily dying'.

The National Consent policy (6.4): …*there will be some individuals for whom no formal DNAR decision has been made, but where attempting CPR is clearly inappropriate because death is imminent and unavoidable, for example, in the final stages of a terminal illness. In these circumstances, it is reasonable for healthcare professionals not to commence CPR"*

There are different situations when a DNAR decision might be made. A DNAR decision must be appropriately recorded on KPFA DNAR decision making form (appendix 2)

The person being supported refuses in advance to CPR. Everyone has a right to refuse CPR if they so wish.

- ✓ The person being supported has indicated they do not want CPR. This decision is recorded on KPFA DNAR decision making form. This form outlines the process of how this decision was made with the person.
- ✓ If the person wants to make this decision legally binding for when in the future they are unable to make this decision, he/she can record same within an Advance Healthcare Directive (appendix 1)
- ✓ When a person lacks decision making capacity and no valid advance health care directive is present, but those close to the person with knowledge of their

previously expressed goals and preferences consider that he/she would not want CPR, a DNAR decision should be documented by the care team if clinically appropriate

- ✓ The person can change their mind about a DNAR at any time. If he/she does, the DNAR on file will be marked as no longer valid and will be stored appropriately to keep record of conversations which happened in the past.

A doctor/senior clinical decision maker (registered medical practitioner) responsible for the person's medical care, decides in advance.

- ✓ In some circumstances, a GP/consultant may make a medical treatment decision and judge that the harms of CPR outweigh the potential benefits and that a DNAR decision is appropriate. This should be recorded on KPFA DNAR decision making form (appendix 2)
- ✓ If a DNAR has been completed by the person's medical team it is important that the person is supported to understand the DNAR
- ✓ It is important that the person's family/circle of support are informed of the DNAR
- ✓ A DNAR does not equate to "doing nothing" and all other appropriate care will be provided.
- ✓ Some DNAR decisions are made in the context of severe acute illness. Such decisions should be kept under review, every 3 months or as appropriate, especially if the person's clinical condition, including their ability to express their own goals and preferences, improves significantly.
- ✓ Other DNAR decisions are made because of severe chronic diseases or where a person is approaching end of life. These circumstances are unlikely to change and it is not necessary that such DNAR decisions are reviewed unless the person wishes and indicates this.

- Where **DNAR** is in place this is highlighted in Red in all Policies, AHD and Care Plans.

10.0 The Process of Care after Death

The process of caring for the body after death has occurred is a way to show our respect for the dead and is focused on fulfilling religious and cultural beliefs. It is a way for an experienced nurse/staff to demonstrate a final act of sensitive care and it includes the following

- ✓ Check their End-of-Life Care Plan or speak to those close to the deceased person about any personal wishes relating to care after death. If known, respect their wishes and any spiritual, religious or cultural practices.
- ✓ Preparing the deceased person for transfer to the Mortuary or Funeral Director (when death occurs in the community).
- ✓ Offering family and carers the opportunity to participate in the process, and providing support to them.
- ✓ Ensuring that the privacy and dignity of the deceased person is maintained.
- ✓ Ensuring that the health and safety of everyone who comes into contact with the deceased is protected (IP&C precautions, including PPE as per PCRA)
- ✓ Respecting people's wishes in the matters of organ and tissue donation.
- ✓ Returning the deceased's personal possessions to their relatives.
- ✓ The environment must conveys respect and respect is also articulated through the attitudes and behaviours of staff when dealing with bereaved people.
- ✓ Ensuring legal obligations are met

Legal Requirements after a person has died

- ✓ The PIC will notify HIQA and the HSE as per legislative guidelines within 3 working days.
- ✓ The death must be registered.
- ✓ The family/key support person will obtain a letter from the person's GP/Hospital confirming date, time and cause of an expected death
- ✓ The family/key support person will register the death by giving the GP letter confirming death and other necessary information to the Register of Births and Deaths in their local area
- ✓ This must be done as soon as possible – no later than 3 months
- ✓ The Death Certificate can be then obtained from the Register of Births and Deaths office for a fee
- ✓ If it has been referred to the Coroner, the family/key support person will liaise with the Coroner's Office.

10.1 The Care after Death Procedure

The personal care after death must be carried out within two to four hours of the person dying, to preserve their appearance, condition and dignity.

1. Nursing staff and person supporting with the procedure will wear appropriate PPE as indicated after completing point of care risk assessment tool.
2. The deceased person's eyes should be closed by applying light pressure for 30 seconds.
3. The deceased person should be placed on their back.
4. The deceased person's limbs should be straightened (if possible) with their arms lying by their sides.
5. Preferably, jewellery should be removed
6. All exuding wounds are to be covered with a clean, absorbent dressing to prevent leaking.
7. An incontinence sheet/pad is to be placed under the lower orifices of the deceased. If there is a catheter present, leave it in situ (unless directed otherwise) and spigot remove the bag and dispose.

8. The mouth should be cleaned to remove debris and secretions. Dentures should be cleaned and replaced as soon as possible after death. If dentures cannot be replaced, they are to be sent with the patient to the Mortuary or Funeral Director in a clearly identified receptacle.
11. Wash the patient unless requested not to do so for religious /cultural reasons.

10.2 Planning Funeral Arrangements for expected deaths

- ✓ All efforts are made to respect the wishes expressed by the individual with regards to their funeral arrangements as outlined in their end of life plan.
- ✓ Manager / Family member/key support person will inform the agreed choice of undertaker.
- ✓ The Person in charge will notify HIQA as per legislative guidelines and the HSE within 3 working days.
- ✓ Ensure the acute hospital, including the members of the multi-disciplinary team, is informed of the person's death so that no further correspondence is sent to the home of the family.

11. Bereavement Support

Bereavement support for the people we support

- The news of the death will be told honestly with a simple factual description of what has taken place, using the correct language associated with death. Avoid the confusion of euphemisms such as 'gone to sleep 'or 'passed on 'which may be misleading.
- Each individual may react differently and will require support accordingly. General support includes being present with the person while acknowledging their sadness and supporting them to grieve.
- Easy read documents or a social story specific to the person may be useful in facilitating the person's understanding of death and supporting the grieving process.
- People we support will be afforded the opportunity to participate in the funeral ceremonies.

- People we support will be afforded opportunities to talk about the deceased, share memories and visit the grave if they so wish.

- Sometimes there may be delayed grief response or unexpressed grief may manifest in other ways and the person may require specialist support. Psychological support is available. Referral can be made to mary.cronin@kpfa.ie .

Bereavement support for the family

- Create an environment where family members feel safe and can express what they are feeling.
- Be specific and practical with offers of assistance, such as providing information on grief support services.
- The family will be offered the option of a removal service in the person's residence and support with contacting an undertaker.
- Support family with understanding the bereaved person's advance care plans in relation to preferences after death.
- Continue to maintain supportive contact with family for a while after the funeral if this is welcome.

Bereavement support for the staff members

- On the day of the death, provide staff with an opportunity to grieve and pay their respects to the individual who passed away.
- Contact staff who are off duty as soon as reasonably possible to allow them pay their respects to the individual if they wish.
- If staff were present for the death of an individual, provide opportunity to debrief before they finish their shift.
- Provide staff with an opportunity to talk about and remember the individual, to reflect on the person's life and what they brought to the lives of others.
- The centre manager should liaise with staff who were on duty at the time of death post event to provide support and an opportunity to talk about it.
- In some instances the need for bereavement support may be identified. This will be provided/facilitated as required.
- Employee Assistance Service (EAS) is in place to support staff
    - Access to EAS directly: Free phone 1800 814 243

Appendix 1 – End of Life Care Planning Tools

[Appendices]

End of Life Care Planning

13. 3.4 Planning for my End of Life: KPFA
14. DNAR decision support form: KPFA (if relevant) appendix 2
15. Glancing Back Planning Forward. Accessible End of Life Tool: Trinity Centre for Aging and Intellectual Disability
16. Glancing Back Planning Forward. How to use the Accessible Planning Tool: Trinity Centre for Aging and Intellectual Disability
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Easy Reads

23. Lets talk about Death. Down Syndrome Scotland
24. Easy Read CPR – KPFA

Appendix 2 – DNAR Decision Support Form

[Appendices]

Appendix 3 – Sudden Death

[Appendices]

12.0 References

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