



Guidance on End of Life Care in social care-led disability residential centres during COVID-19

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Target audience:

Person in Charge and staff members supporting service users in social care-led disability residential setting.

Purpose of this guidance

- To ensure those working in and managing disability social-care led residential services in the current COVID 19 pandemic are aware of their role in responding to and addressing the end of life care needs of residents and in doing so, are supported to have an active/supportive role.
- To provide key information on the HSE Operational Pathways of Care for the assessment and management of people with Covid-19 and the National Palliative Care Model of Care pathway as they relate to social care-led disability residential centres during COVID 19
- To give practical guidance to staff supporting and providing end of life care to residents in a disability social -care led residential care settings, in line with normal pathways, during the current COVID-19 pandemic.

The document gives advice on care AFTER any decisions about end of life care have been made by an appropriate clinicians e.g. GP or other physician. It does not suggest that this is the approach to be taken in general terms in disability residential settings. It relates to end of life care for COVID 19 related illness and non-COVID 19 related illnesses.

Please be aware that within the changing nature of the epidemic clinical guidance regarding management may change quite quickly. Keep updated and refer to the following websites regularly for updates:

www.hse.ie/coronavirus HSE's webpage with a broad range of information on Covid-19

www.hpsc.ie : HSE's Health Protection and Surveillance Centre website with up to date guidelines and information

<https://hse.drsteevenslibrary.ie/Covid19V2> : Repository of Covid 19 Clinical Evidence and Guidance (updated daily)

All HSE Guidance and Resources for Disability Services are available on:

<https://www.hse.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources/>

This guidance should be read in conjunction with the documents from the **Palliative Care Programme** and those on managing COVID 19 in residential settings including disability settings, which are located on the links

above. An overview of the current (as at 21/04/2020) and most relevant material that you may wish to read in conjunction with this document is listed in Appendix 1.

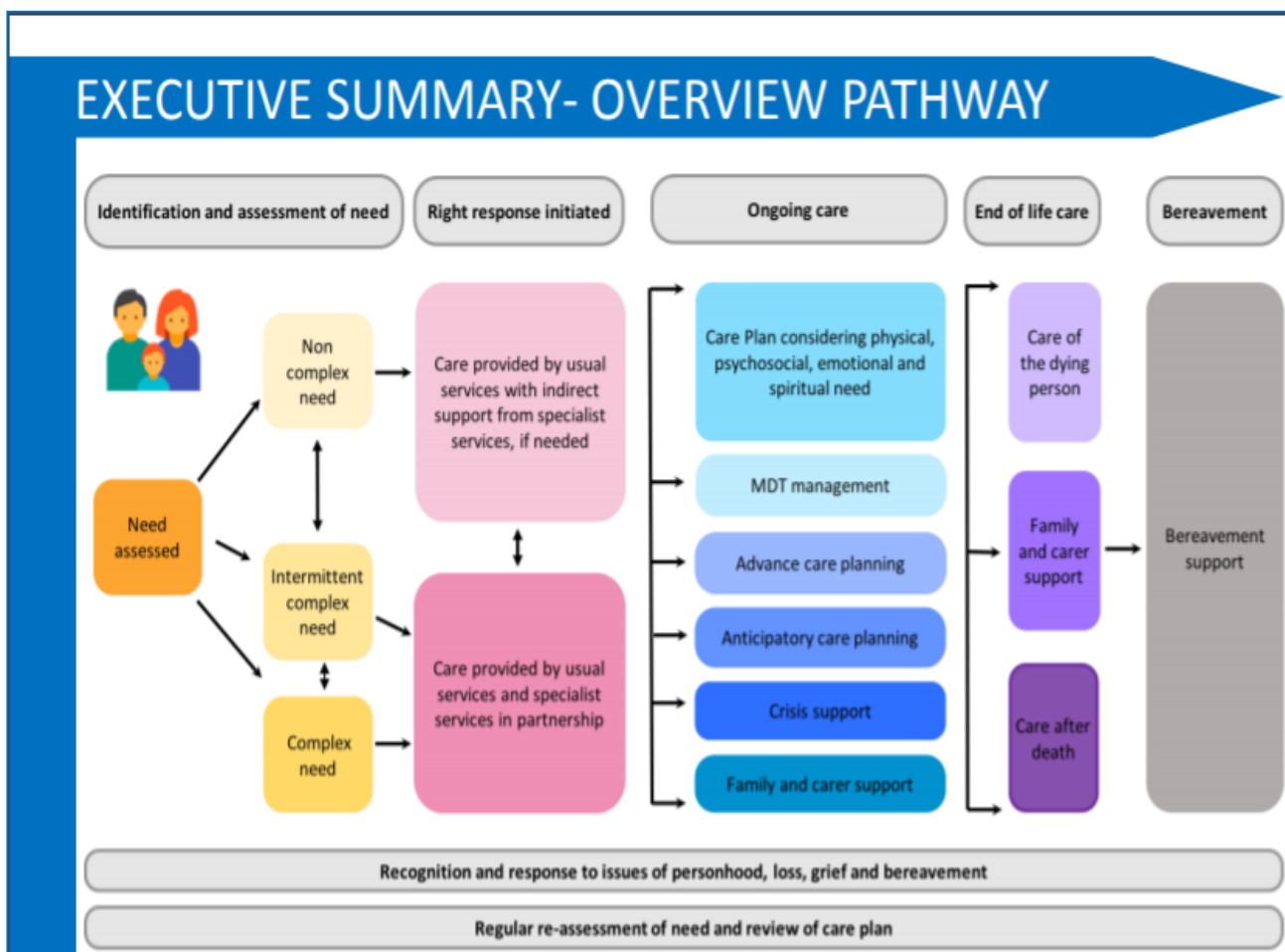
Recognising the rights of people with Disability

Understanding the rights of people with disability to access services and supports equal to all other citizens is essential in the current crisis.

Neither an intellectual disability, nor any other type of disability by itself, means that the person is more vulnerable to COVID-19, unless they have other medical co-morbidities. In the current crisis, some people may have medical vulnerability factors and have other support needs that require particular attention. It is essential that for all people their disability status is separated from their health status and other factors, such as their degree of dependency, their capacity or the impact of the particular residential arrangement they are living in.

Adult Palliative Care Services Model of Care for Ireland

In Ireland the model of palliative care is that, *“Every person with a life-limiting or life-threatening condition can easily access a level of palliative care appropriate to their needs regardless of care setting or diagnosis in order to optimise quality of life”*. [Below is the overview pathway from the Model of Care from the document, https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/moc/ncp-palliative-care-model-of-care-24-04-0219.pdf](https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/moc/ncp-palliative-care-model-of-care-24-04-0219.pdf)



Not every person needs the involvement of specialist palliative care services at the end of life. Many people are supported in their homes or long stay residential settings at the end of their lives by their GP and the nursing and care staff, without specialist intervention. The National Palliative Care programme have developed a Palliative Care Needs Assessment Guidance that focuses on four domains: Physical Well-being, Social and Occupational Well-being, Psychological Well-being and Spiritual Wellbeing. This is a good resource for staff and families and prompts discussions. There is an A4 poster version of the guidance, which can be used and displayed in services to guide staff. This is included in Appendix 2 along with links to the website where both the full document and poster are located.

The HSE intends to continue to provide specialist palliative care (SPC) input to all settings as they would normally do. However, like every other service, this will be dependent on resourcing (staff) and prioritising of need. Community SPC services will provide conferral advice, assess need and visit as determined necessary. The normal community palliative care team comprises 5-6 nurses providing 7 day a week (9-5) input across a population base of 120,000- 160,000 across 1 or more counties (outside Dublin and Cork). A vital part of the care is an involved GP (to assess patients medically and prescribe as needed).

Palliative and End of Life Care

Palliative care is an approach to care focusing on promoting comfort through relieving pain and other symptoms. The aim of palliative care is to enhance the quality of life of those living with life limiting progressive conditions and their families. End of Life Care refers to all aspects of the care relating to dying, death and bereavement which is provided towards the end of life.

Links to Palliative Care Services in Ireland

The HSE has responsibility for providing palliative care services; contact your [Local Health Office](#) to find your local palliative care team. <https://www.hse.ie/eng/services/list/1/lho>

The Irish Hospice Foundation has a [local services directory](#), <https://hospicefoundation.ie/supporting/wayswesupport/directory-of-local-services/>

This gives all palliative care services, county by county. This directory also gives contact details for local support groups for patients and their families.

[The Palliative Hub](#) provides information and resources on palliative care on the island of Ireland.

How do we support a person with an intellectual disability at the end of life?

Below the key elements of the *Ambitions for palliative and end of life care* framework are set out, to identify what staff can do to improve the experience of people they support when they are coming to the end of their lives. For Social Care staff, particularly those that know the residents very well, communicating with residents and their families at this time will be key and there is a short guide to this in Appendix 3.

Each person is seen as an individual

Like everyone else, people with disabilities should have the opportunity to take part in conversations about death and dying. It is important to talk to the person about their end of life preferences and needs. This will take several conversations. Like others they are likely to be anxious and afraid. Support the giving of

information to the person about their illness and symptoms in a way they are best able to understand. There are easy-read and accessible documents that can be used to help with this. See Appendix 5 for useful links.

Each person gets fair access to care

When someone with intellectual disabilities is coming to the end of their life, think about the “reasonable adjustments” the person might need to support them. For example, people with intellectual disabilities may require clear, simple and possibly repeated explanations of what is happening, and of treatments to be followed. Staff should take care not to make assumptions, but consider and plan what might be needed, working with the person. If the person is going to have treatment in hospital or in a hospice, help them to prepare. See Appendix 5 for useful links to information sheets, easy read resources and up to date online webinars that may help and support staff with these actions.

Maximising comfort and well-being

Staff should follow the guidance of clinician and palliative care services in terms of what can be done to make the person more comfortable. In Appendix 8, the one-page guide on *Non-pharmacological care in the last hours or days of life* provides an overview of the type of supports and symptom management that can be appropriate, such as whether a person should eat or drink, positioning in bed, their environment, mouth and eye care etc. In Appendix 9, there is a practical guide targeted at carers and family members, which may be useful for social care staff in residential settings to know what to expect and how to make the experience of the person as comfortable as possible.

Care is co-ordinated

There may be many people involved in supporting someone at the end of their life, particularly if they have several medical conditions. This needs to be co-ordinated to work well for the person. Make sure you know who is taking the co-ordinating lead, this may be a GP or an end-of-life care nurse. Support workers can help by having good information about the individual so everyone knows things like how they communicate and their likes and dislikes. This might be a health passport or an ‘All about Me’ document.

All staff are prepared to care

Supporting someone at the end of their life can be very challenging. For staff, this may be made more challenging due to the current COVID 19 pandemic for a range of reasons such as social distancing, PPE use, availability /access to other professional supports, changes in care pathways etc. Staff may need emotional support. At the current time support is available through a **dedicated Healthcare worker COVID-19 helpline (Callsave 1850 420 420)**. The helpline will assist staff with information and advice to protect their own health and wellbeing during this period.

Each community is prepared to help

Think about what services there are in the community that could help. Care and support may also be needed by the person’s family/friends. Local health, care and community voluntary organisations may be able to help with this during the current social distancing restrictions. The Government announced the **Community Call** on 2 April. The purpose of Community Call is to co-ordinate local services and make them easy to access for people who need them. Local authorities have set up local **Community Response Forums** in each local authority area. You can call a national number, which is being managed by the charity Alone **0818 222 024**. This number is available from 8am to 8pm, Monday to Sunday. Alternatively, go to the following link for further information:

https://www.citizensinformation.ie/en/health/covid19/community_support_during_covid19.html

Key considerations when supporting a person during End of Life

- All decisions regarding a person's 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.
- All communication must be through means that are most appropriate to the service user. Residential services staff who know a person have a key role to play in supporting effective communication with them. Sufficient time and communication aids should be used to support good communication.
- Staff supporting and contributing to discussions of end of life care need to be appropriately skilled to do so. These discussions will normally be led by the nursing and medical staff, the person's GP and/or medical consultant.
- Significant and coordinated holistic support is needed to ensure that the person ends their life with dignity, free from pain and in a place of their choosing.
- Ensuring that there is an awareness of each person's wishes and needs as an individual. It is important that their needs are understood and met where appropriate.
- Where the person is unable to provide details of their problem and symptoms due to for example a cognitive impairment, the symptoms and history may be provided by the carer/ professional caring for the person or a family member/close friend.
- Making sure the person is comfortable and minimising distress is an important part of care.
- Recognise that although everyone has different views what constitutes a good death for many would involve being in familiar place and in the company of close family and friends. Close support workers may have a role in this due to restrictions during the current COVID 19 crisis.
- A care pathway will form part of the Support Plan of the person as they reach end of life. This will be led by the clinician (the GP, Medical Officer or Consultant) supported by the staff working with the person. The purpose of the plan is to identify the person's status and respond appropriately. It will ensure a clear record of a person's needs and identify how these will be managed in the current crisis in line with care pathway guidelines. See Appendix 4 for further guidelines on the content.
- The needs of others (for example, where the person shares a house), including the needs of peers to understand what is happening and the needs of staff for support to continue to provide appropriate care
- **Service Managers (PICs) should be mindful of the following parameters of response:**
 - When there is a need for additional senior nursing and / or medical review and the access pathway to secure this support/intervention.
 - Putting an observation protocol in place that can be managed relative to your available staff and skillset and the needs of the resident at end of life.
 - Stay in regular contact with the resident's family
 - Refer to the Person Centred Plan, Personal Support Plan, and Advance Care Plan
 - Ensure a person's health passport includes their advance care plan where this is in place
 - Staff do not have to make/ manage decisions outside their scope of practice and training
 - Be aware that deterioration with COVID 19 can occur very rapidly
 - **Know the local care pathway and have links established , especially if transfer out of the setting is being considered**
 - **Identify the process for staff accompanying a person transferring if required**
 - Hospitals are still open to receive patients and ensure everyone gets the right treatment

A note on Advanced Care Planning and End of Life Decisions

Advance Care planning is a process of discussion and reflection about goals, values, and preferences for future and end-of-life care. **This process usually takes place with a doctor or nurse**, but all services can support the person to indicate what they would like/not like to happen in relation to different aspects of their healthcare, should the need arise, including at the end of life.

Although advance care plans are not legally binding, they help to inform a person's family, friends and doctors of their wishes in the event they can no longer communicate. A statement on Advance Care planning is due to be released shortly and will be available on the HSE website, which can be checked for updates.

The Irish Hospice Foundation's Think Ahead form provides a template for advance care plans. There is also an easy read version of this developed by IDS TILDA. See Appendix 5 for links.

Decisions about CPR

The National Consent Policy Part Four) on when to and when not to attempt resuscitation provides guidance on the decisions about CPR, noting:

Decisions about CPR must always be made on the basis of an individual assessment of each case and not, for example, on the basis of age, disability, the subjective views of healthcare professionals regarding the individual's quality of life or whether he/she lives in the community or in long-term care. The individual's own views and values are centrally important..... it is also necessary to consider the likelihood of CPR being successful as well as balancing the benefits and risks involved.

The policy goes on to state

If a person has decision-making capacity then his/her family or friends should only be involved in discussions regarding his/her treatment and care with that individual's consent. If the individual is unable to participate in discussions due to his/her physical or cognitive condition, those with a close, on-going, personal relationship with the individual may have insight into his/her previously expressed preferences, wishes and beliefs....

However, the role of those close to the individual is not to make the final decision regarding CPR, but rather to help the healthcare professional to make the most appropriate decision. Where CPR is judged inappropriate, it is good practice to inform those close to the patient, but there is no need to seek their 'permission' not to perform CPR in these circumstance

CPR and COVID 19

CPR is an aerosol generating procedure (AGP) which carries significant risk of infection transmission to healthcare workers in the case of persons with COVID 19. In the event that CPR is being undertaken, staff should have access to appropriate PPE. There is guidance on CPR on the HSE's Repository of Clinical Evidence and Guidance at <https://hse.drsteevenslibrary.ie/Covid19V2>



Algorithm for social care-led settings where the decision has already been made that a person requires end of life care during COVID 19 pandemic

WHAT STAFF SHOULD ENSURE THEY KNOW

- Resident's current health & wellbeing status
- Clinical decision & guidance agreed and in place specifically for the person
- Advance Care plan that will guide decisions
- Key contacts
- Escalation and current care pathway
- Current PPE protocols

Pathways
Managers to stay updated and keep staff advised on:

- COVID 19 testing pathway
- Current agreed care pathway for those living in this location who require additional care /nursing support (+/- COVID-19)
- Current agreed end of life care pathway for those living in this location who require additional care /nursing support (+/- COVID-19)
- Process and pathway for pronouncement of death and care of the person after dying

Key Contacts
Consider:

- Family members, Friends, Advocate
- Person in Charge > Service Manager > Local HSE Disability Manager
- Contact on the COVID-19 Crisis Response Team
- GP,
- Local Palliative Care Nurse/Service

For up to date information and guidelines for disability residential centres go to <https://www.hse.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources/>

Stay up to date on www.hspc.ie for guidelines on PPE use

For contact details for palliative care services go to <https://hospicefoundation.ie/supporting/wayswesupport/directory-of-local-services/>

For up to date information on clinical pathways and guidelines go to on <https://hse.drsteevenslibrary.ie/Covid19V2>

Is it suspected or confirmed that the person has COVID-19?

WATCH out for SIGNS of COVID-19
These might include changes in the person's:

Respiratory status:
New or worsening cough
New or worsening shortness of breath
New or increased sputum

Mental State:
New signs or symptoms of increased confusion/delirium
Decreased level of consciousness
Inability to perform usual activities
New or worsening unexplained agitation
New or worsening delusions or hallucinations

Altered body temperature
Refer to COVID-19 guidelines

YES

ACTIONS NEEDED

- Isolate the person and use PPE as recommended
- Assign staff to support the person in isolation
- Contact GP to order testing
- Contact Public Health/Medical Officer
- Follow escalation protocol to alert COVID 19 Crisis Response Team in CHO

NO

ACTIONS NEEDED

- Refer to ACP and anticipatory guidance
- Stay in regular contact with family
- Set an observation protocol in place that can be managed relative to your staff skill set and availability
- Be aware that deterioration can happen quickly
- Consider and continue to review the need for additional nursing or medical review and support
- Communicate in line with the person's communication passport and where appropriate using **ISBAR** tool

Identify yourself and Location
Situation
Background- tell story
Assessment- what is going on?
Request- what you want