



## **Appendices**

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

Appendix 1: Current Relevant Guidance

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Appendix 3: Communication and Engagement Notes

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Appendix 7: HSE Care Pathway during COVID19

Appendix 8: Non Pharmacological support in last days/ hours of life

Appendix 9: Practical advice for carers and families of a person at the end of life

## Appendix 1: Current Relevant Guidance

### General Guidance for COVID-19 in Social Care Group Homes and Residential Care Services – Disabilities

There is a guidance document available in relation to delivering ongoing care in residential settings where the main model of care delivery is non-medical, during the current COVID-19 situation. This guidance notes that services should implement isolation precautions when someone in the home displays symptoms of COVID-19 in the same way that they would operate if an individual had influenza. The guidance notes that if a dedicated isolation facility is required and not available in the home or across the organisation, the matter should be escalated to the local Disability Manager for follow up in line with HSE Operational Pathways of Care for the assessment and management of patients with Covid-19.

This can be accessed at the link <https://www.hse.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources/>

### Infection Prevention and Control Guidance

All staff are aware and up to date on the Preliminary Coronavirus Disease (COVID-19) Infection Prevention and Control Guidance include Outbreak Control in Residential Care Facilities (RCF) and Similar Units available at the following HPSC link

<https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/guidance/infectionpreventionandcontrolguidance/residentialcarefacilities/RCF%20Guidance%20March%2021%202020%20Final%20noag.pdf>

### Safe and appropriate use of PPE is essential for all healthcare workers

Please refer to the HPSC website [www.hpsc.ie](http://www.hpsc.ie) for the most up to date guidance, as this is being updated regularly. There is specific guidance on PPE use in residential services and community services. On the disability resources webpage there is specific guidance in relation to PPE use by staff and residents in disability settings. <https://www.hse.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources/>

You are encouraged to complete the HSE-land module on **Putting on and Taking off PPE in the Community Healthcare Setting** by logging onto HSE land on the following link

<https://www.hseland.ie/dash/Account/Login>

It only takes about 10 minutes to complete and there is certification following self assessment

### Non-Pharmacological Care in the last hours/days of life

This one page guide is a useful reference for staff working with people and their families at the end of life. It is available to view in the *HSE's repository of clinical evidence and guidance* and is included in Appendix 7

## Enhanced Public Health Measures for COVID-19 Disease Management: Long term Residential Care (LTRC) and Home support

These measures introduced on 1st April 2020 include residential and home support services for people with disabilities. The measures aim to support the maintenance of residents in LTRC unless there is clinical or other advantage and to interrupt and prevent the onward transmission of the disease.

The measures include training in palliative care and end of life for staff in LTRC and the provision by the HSE of PPE and oxygen to these settings. See Appendix 5 for full list of measures.

## Operational Pathways of Care for the assessment and management of patients with Covid-19

Under the HSE Operational Pathways of Care directive, each CHO is required to have in place a plan to identify the care pathway for all individuals that develop COVID-19. This needs to include all people with disabilities living in residential services in their area.

The services in each CHO area are different with a mix of voluntary and HSE services, nurse led and/or social care led, congregated and/or community etc. Senior managers within the service providers will need to liaise with the Head of Disability Services in their CHO to identify how the care pathway is being implemented in their area. This should include clarity on the location of intermediary residential facilities, the access criteria /pathway to these for residents, access to additional care supports including nursing and GP support and palliative care supports. See Appendix 6 for Overview of the HSE Care Pathway.

## HSE COVID Residential Care/Home Support COVID Response Teams CRT Operational Guidance

This guidance was released on 8<sup>th</sup> April 2020. NPHE (National Public Health Emergency Team) have directed the requirement to have such teams in place to ensure Residential Care/ Home Support service Covid-19 outbreaks are supported. The full document can be accessed at the following link [https://www.pna.ie/images/Covid%20Response%20Teams%20%20Operational%20Guidance%20080420%20\(3\).pdf](https://www.pna.ie/images/Covid%20Response%20Teams%20%20Operational%20Guidance%20080420%20(3).pdf)

The guidance states that,

*As part of the HSE COVID 19 response, there is a requirement on each of the Area Crisis Management Teams (ACMT) to establish a number of Residential Care & Home Support Covid-19 Response Teams (CRT) to address COVID -19 outbreaks in their area. Such outbreaks are determined by Public Health, and where there are three or more positive cases.*

*The purpose of these CRTs will be to support the prevention, identification, and management of COVID 19 outbreaks across residential care facilities and Home Support services. The teams will provide support across a range of nursing and medical care areas as well as Infection Prevention and Control. These teams must support all residential care facilities/Approved centres in the catchment area whether they are public, S38, S39 or private facilities, and across the care groups of Older People, Disability, & Mental Health. In addition, they will also address identified clusters of concern in the Home Support services, as determined by Public Health.*

*The teams will operate for the timescale of the COVID 19 Public Health emergency. The CHO area will require multiple teams based at LHO, or county level, depending on the number of centres in the area. These teams will support facilities to maximise care they provide to residents, relative to their available levels of expertise, which will vary across care settings. This will bring benefits to residents/clients for both Covid-19 related & non-Covid-19 related illness during this pandemic. The governance and management of each centre is the responsibility of each provider, in accordance with Regulations (HIQA /MHC). The CRT's role is to support these centres, as far as possible, while ensuring that the responsibility for the operation of the services and adherence to the regulation must rest with the Registered Provider.*

## **Ethical Framework for Decision Making in a Pandemic**

This document has been drafted by the Government. The document advises,

*“this ethical framework includes a number of substantive ethical principles and procedural values that can be applied to, and employed during, the decision-making process in a pandemic. Ethical principles apply to the decisions that are made, whereas procedural values relate to the manner in which those decisions are made.*

*This high-level framework is intended for policymakers and healthcare planners and providers in acute and community settings. It is also designed to assist clinicians in implementing the ethical principles outlined below in their clinical practice. It is not designed to guide individual clinical decisions but to assist healthcare workers in thinking through the difficult decisions that will need to be made.*

The framework can be accessed at: <https://www.gov.ie/en/publication/a02c5a-what-is-happening/#ethical-framework-for-decision-making-in-a-pandemic>

## **Requirements for death pronouncement and care of the deceased**

In the current COVID-19 pandemic there are amended guidelines and requirements with regard to death pronouncement and the process following death. Further changes may arise and services are advised to check relevant websites for updates: [www.coroners.ie](http://www.coroners.ie)

The HPSC provides guidance and updated information on the care of the deceased and onward care of human remains. Services are advised to check the HPSC website regularly for updates. <https://www.hpsc.ie>

## Appendix 2: Palliative Care Needs Assessment Guidance

### PALLIATIVE CARE NEEDS ASSESSMENT GUIDANCE

#### DOMAIN 1: PHYSICAL WELL-BEING

Patients with life limiting conditions frequently have multiple symptoms. Patient self report of symptoms varies from person to person. Some physical symptoms are readily reported by patients while others often require prompting. Some of the frequently encountered physical problems in the last year of life are outlined in table 1.

Table 1 Frequently Encountered Physical Problems in the Last Year of Life

Frequently encountered physical problems in the last year of life	
Pain	Somatic, visceral, neuropathic Take a detailed pain history outlining <ul style="list-style-type: none"> <li>Location, quality, intensity, duration, frequency</li> <li>Associated/aggravating/relieving factors</li> <li>Treatment interventions to date</li> </ul>
Fatigue	Fatigue disproportionate to level of activity or not relieved by rest
Respiratory	Dyspnoea, cough, oropharyngeal secretions
Gastrointestinal	Anorexia, nausea, vomiting, constipation
Neurological	Insomnia, confusion, delirium, anxiety, depression
Other	Functional status, balance problems, oedema, wound problems

*This is neither a prescriptive nor an exhaustive list- it serves to illustrate the variety of physical problems encountered and need for systematic assessment to identify physical problems*

#### Approach:

- An introductory question to prompt the person to identify the physical needs of most concern to them.
- Thereafter a thorough and careful systems review will determine the presence and severity of physical symptoms.

#### After identification of symptoms:

- Elicit a history of symptoms including previous treatments received.
- Ascertain the effect of the problem on the patient's normal activities function.
- Consider treatment options.

#### Action:

- Agree and implement a care plan with the patient and multidisciplinary team.
- Establish whether these symptoms can be managed by the current treating team.
- If severe or intractable physical problems are identified or anticipated, consider referral to the specialist palliative care service.

#### DOMAIN 2: SOCIAL AND OCCUPATIONAL WELL-BEING

The family is the unit of care. When assessing patients with life-limiting illness it is important to explore their concerns in relation to their home, family and community, and to identify risk in relation to their autonomy and social functioning.

#### Approach:

A social assessment seeks to gain some understanding of an individual's life experience with regard to their:

- Background,
- Family support,
- Emotional and social support,
- Practical concerns.

Table 2 Suggested Prompts; Social and Occupational Well-being Assessment

Suggested Prompts	
Family Support	Invite discussion about family and relationships: <ul style="list-style-type: none"> <li>Who lives with you?</li> <li>Any children/adult dependents?</li> <li>any concerns/worries regarding family or personal relationships?</li> </ul>
Emotional and social support	Do you have any other support for example PHN, home help, private carers, friends, neighbours? <ul style="list-style-type: none"> <li>How often do you see them?</li> <li>Do you need more support?</li> <li>What would help?</li> </ul>
Practical concerns and advance care planning	Discussion about practical issues: <ul style="list-style-type: none"> <li>How are you managing?</li> <li>Any difficulties in: mobilising, managing the stairs, household chores e.g. washing, cooking, etc?</li> <li>Any concerns about future care needs, income, finances, sorting out your affairs?</li> <li>What are the person's wishes regarding:               <ul style="list-style-type: none"> <li>Goals of care?</li> <li>Acceptable levels of intervention?</li> <li>Preferred place of care (person and family)?</li> </ul> </li> </ul>

#### After identification of concerns:

- Ascertain the effect of the problem on the patient's normal activities function.
- Consider treatment options.

#### Action:

- Agree and implement a care plan with the patient and multidisciplinary team.
- Establish whether these symptoms can be managed by the current treating team.
- If severe or intractable physical problems are identified or anticipated, consider referral to the specialist palliative care service.



### DOMAIN 3: PSYCHOLOGICAL WELL-BEING

Patients with life limiting conditions frequently have psychological concerns. In order to identify these concerns, it is important that the assessor is proactive in asking about emotional and psychological issues.

**Approach:**

Begin with an open exploratory question that invites the person to identify any concerns. "Is there anything worrying you?"

Followed by consideration of the following:

- Mood and interest
- Adjustment to illness
- Resources and strengths
- Uncontrolled multidimensional pain (total pain)
- Pre-existing mental illness

Table 3 Suggested Prompts; Psychological Well-Being

Suggested Prompts	
Mood and interest	<ul style="list-style-type: none"> <li>• How is your mood?</li> <li>• During the last month have you:                             <ul style="list-style-type: none"> <li>– been feeling down and/or hopeless?</li> <li>– lost enjoyment in interests?</li> </ul> </li> <li>• Are you depressed?</li> <li>• Do you feel tense or anxious?</li> <li>• Have you ever had a panic attack?</li> <li>• Are there things you are looking forward to?</li> </ul>
Adjustment to illness	<ul style="list-style-type: none"> <li>• What is your understanding of your illness?</li> </ul>
Resources and strengths	<ul style="list-style-type: none"> <li>• What is a source of support for you?</li> <li>• Look for a range of possible supports: people, hobbies, faith, beliefs</li> </ul>
Total pain	<ul style="list-style-type: none"> <li>• Uncontrolled multidimensional pain e.g. psychosocial, emotional, spiritual pain, consider if distress contributing to physical symptoms</li> <li>• Are there psychological, social, emotional, spiritual issues that may be contributing to symptoms?</li> </ul>
Pre-existing mental illness	<ul style="list-style-type: none"> <li>• Persons with a history of current or past mental health problems may be particularly at risk of psychological distress</li> </ul>

**After identification of concerns:**

- Elicit history of concerns including previous supports/interventions received.
- Ascertain the effect of the problem on the patient's normal activities/function.
- Consider treatment options/interventions.

**Action:**

- Agree and implement a care plan with the patient and multidisciplinary team.
- Establish whether these needs can be managed by the current treating team.
- If significant complex family and social concerns are identified or anticipated, consider referral to the Specialist Palliative Care Service.

### DOMAIN 4: SPIRITUAL WELL-BEING

People have many different understandings to the word spiritual and how it impacts on their lives. When completing spiritual assessment, assessors need to be aware of alternative terms i.e. faith, belief, philosophy, religion, inner strength.

**Approach:**

An introductory question/s to alert individuals to a change in focus from clinical is required e.g. How has this illness impacted on your life? The following is a suggested approach to assessment:

Table 4 Suggested Prompts: Spiritual Well-Being Assessment

Suggested Prompts		
H	Sources of hope	What gives you hope (strength, comfort peace) in the time of illness?
O	Organised religion	Are you part or member of religious or spiritual community? Does it help you?
P	Personal spirituality & practices	What aspect of your spiritual beliefs do you find most helpful and meaningful personally?
E	Effect on medical care and end of life issues	How do your beliefs affect the kind of care you would like me to provide over the next few days/weeks/months?

**After identification of concerns:**

- Elicit history of concerns including previous supports/interventions received.
- Ascertain the effect of the problem on the patient's normal activities/function.
- Consider treatment strategies/interventions.

**Action:**

- Agree and implement a care plan with the patient and multidisciplinary team. This may include referral to pastoral care service.
- Establish whether these needs can be managed by the current treating team.
- If significant complex spiritual concerns are identified or anticipated, consider referral to specialist palliative care service.



See Palliative Care Needs Assessment Guidance accessible on [www.hse.ie/palliativecareprogramme](http://www.hse.ie/palliativecareprogramme)  
 NATIONAL CLINICAL PROGRAMME FOR PALLIATIVE CARE

## Appendix 3a: Communication- Breaking Bad News

### Breaking Bad News

The HSE has an online resource for dealing with breaking bad news

<https://www.hse.ie/eng/about/who/qid/resourcespublications/tool-box-talks/end-of-life-care-dealing-with-bad-news.pdf>

There are a number of key practical steps including:

#### Never deliver bad news alone

It is better for you and the recipient if there is more than the two of you present

#### Prepare yourself

Set time aside find a quiet room. Never give important information in inappropriate places

#### Build on the person's/family knowledge

Start by sitting down at the person's level, introduce yourself. Find out what the person knows

#### Break the news

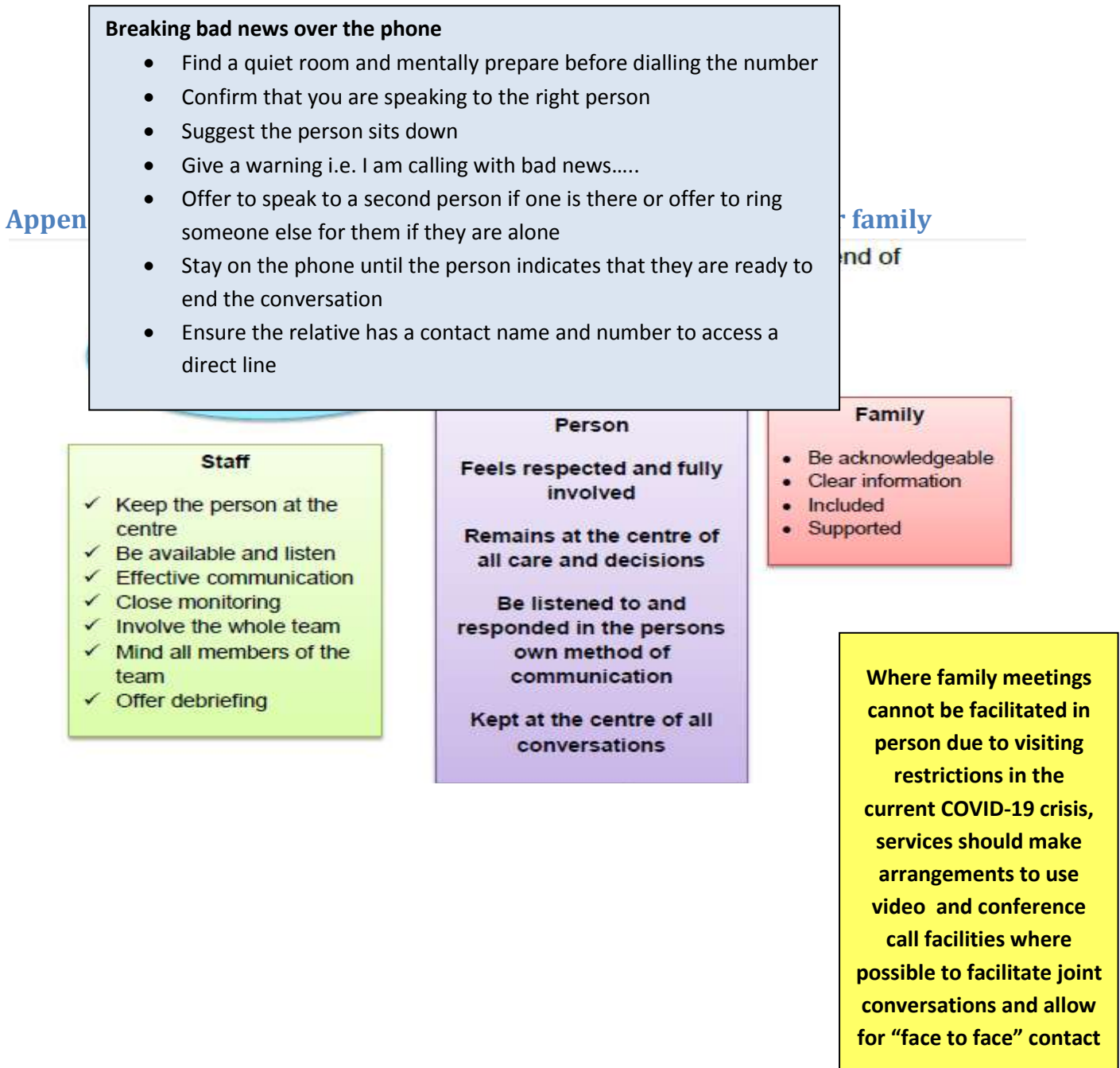
Break the news gently, slowly and clearly. Don't overload the person with information. Use simple language. Before ending check if the person understood and if necessary repeat the information again.

#### Support the person and their family

Allow for emotional reactions – avoid false reassurances. Deal with concerns before details

### Plan and follow up

Give the person and their family a clear plan as to what will happen next



## How we care for loved ones as they approach the end of life.....

*Family is whoever the person says it is*

*Family can be defined as 'those closest to the person in knowledge, care and affection'*

All communication should be at the expressed wish of the person but where this is not possible by the best intentions of the person

Clear decision making processes should be in place and should be adopted by all staff

Information should be given in a sensitive and planned way

Communicate regularly with the family

Prepare families especially when death is imminent

### Support to Family

Fundamental to good end of life care we give to the family of the person we are caring for before, during and after death. While we always keep the person at the centre of care, person centred care includes family care

Families need time, space, privacy and compassion. Family meetings can provide opportunities to create a shared approach to the care of the person who is dying and allow time for staff to clarify each person's understanding of their loved ones diagnosis

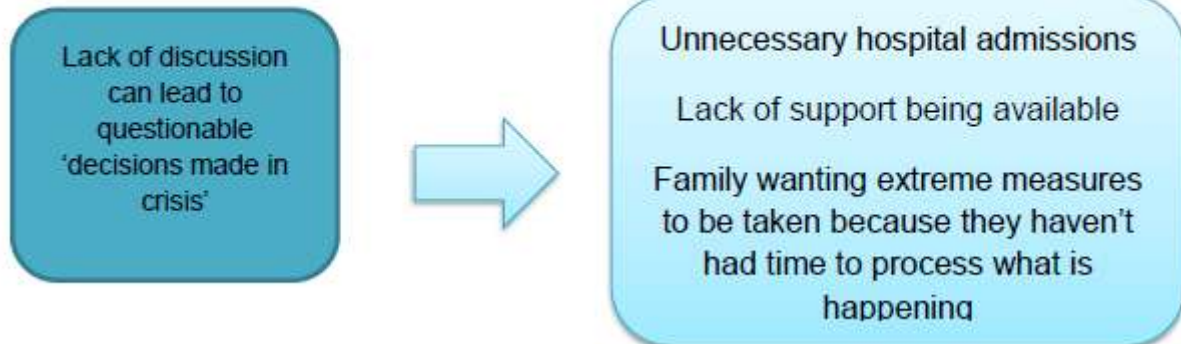
*Support offered to families should encompass the domains of care represented below*





## Appendix 3c: Communication- Responding to Difficult Questions

Research has found that end of life care decisions made too close to death can cause unnecessary stress for both the person and their families (TILDA 2017)



When a person or family is concerned about something and they want to talk to someone they will choose who to speak to

If someone is seeking to talk to you it's because they believe you can help

Your job is to accept that trust and explore their concerns

Be an active listener

Give your full attention to the person

Be aware of your body language – sit down with the person

Maintain good eye contact

Don't interrupt even if silences occur

Paraphrase

Don't pretend to understand their perspective if you don't

Acknowledge the person's concerns

*The difficulty in responding to difficult questions can often be our own anxiety about having the right answer for the person and wanting to make them feel better.*

### Important points to remember

#### Don't panic

**Don't avoid the question or aim to close it down with well-meaning euphemisms**

**Keep communication open in as far as you can**

**Don't rush a response based on your own discomfort**

**It's okay to say 'I don't know' if you don't know**

**Refer to someone who does know**

It is useful to be aware that there are a number of questions families often ask. These are included in the *Non-pharmacological care guide* in Appendix 7

#### QUESTIONS FAMILY MEMBERS OFTEN ASK

- ✓ How long has (s) he got?  
*"We can't be certain, but it's likely to be within a few hours or days at most. What would you like for her?"*
- ✓ Can (s)he still hear?  
*"We don't know for sure but if you would like to say something, now is the time"*
- ✓ How will you know if (s)he has pain?  
*"We will watch carefully for signs of distress. We will give whatever medication is needed to keep him/her pain free and comfortable"*
- ✓ Is (s)he dying of dehydration or starvation?  
*"At this time, all of the vital organs including his heart and kidneys are shutting down. His/her body cannot cope with food or fluid right now."*

## Appendix 4: Guideline on documentation to support the End of Life Care plan

- Current assessments can be reviewed, where there are no changes a review will suffice i.e. date and sign review section of assessment and / or health action plan
- Assessments by medical, nursing and multi-disciplinary team should be included
- Any relevant individualised meetings to discuss care i.e. multi d meetings, PCP's meetings with GP and families should also be included
- Relevant GP notes regarding deterioration in health status
- If an Advance Care Plan has been completed, this information should also be included within the management plan
- DNAR written by GP or consultant should be included within the plan
- Information relevant to end of life care i.e. specialist palliative care

## Appendix 5: Additional resources and links, Easy Reads and links to practice guidelines

Theme	Description	Provider	Link
<b>Guidance and information</b>			
Bereavement and Learning Disability	Guide for professionals offering bereavement support	Keele University	<a href="http://www.bereavementanddisability.org.uk/">www.bereavementanddisability.org.uk/</a>
Living and Dying with Dignity	Ensuring people with disabilities receive inclusive end of life care services	Mencap	<a href="http://www.mencap.org.uk/all-about-learning-disability/information-professionals/health/end-life-care">www.mencap.org.uk/all-about-learning-disability/information-professionals/health/end-life-care</a>
Symptom Management	Symptom management end of life care pathway and guidance	Haringey Learning Disabilities Partnership	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=312">www.improvinghealthandlives.org.uk/adjustments/?adjustment=312</a>
End of Life Care	Dementia and end of life	Alzheimer's society	<a href="http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=428">www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=428</a>
Breaking Bad News	A suite of resources for use by practitioners, families and carers	Breaking Bad News	<a href="http://www.breakingbadnews.org/">www.breakingbadnews.org/</a>
Six Steps Structure	A programme for care homes to deliver the best end of life care	NHS Cumbria and Lancashire End of Life Care Network	<a href="http://www.endoflifecumbriaandlancashire.org.uk/six_steps.php">www.endoflifecumbriaandlancashire.org.uk/six_steps.php</a>
North West End of Life Care Model	Story of a patient's health from diagnosis to life limiting illness	NHS Cumbria and Lancashire End of Life Care Network	<a href="http://www.endoflifecumbriaandlancashire.org.uk/info_health_socialcare_professionals/model.php">www.endoflifecumbriaandlancashire.org.uk/info_health_socialcare_professionals/model.php</a>
Decision making	Deciding Right guide to support compliance with BMA/ Resuscitation Council/RCN joint statement on cardio-pulmonary decisions, NHS guidance on advance care planning and Mental Capacity Act	NHS England Northern Clinical Networks and Senate (End of life care network)	<a href="http://www.cnne.org.uk/end-of-life-care---the-clinical-network/decidingright">www.cnne.org.uk/end-of-life-care---the-clinical-network/decidingright</a>
Distress assessment	DisDAT tool provides means to document individual's language of distress, monitor their distress and evaluate its cause	St. Oswald's Hospice and Tyne & Wear NHS Trust	<a href="http://www.stoswaldsuk.org/adults/professionals/disdat/Background%20to%20DisDAT/">www.stoswaldsuk.org/adults/professionals/disdat/Background%20to%20DisDAT/</a>

## Easy Read Resources

All the easy reads below are available on the Be.Macmillan website

<https://be.macmillan.org.uk/be/s-853-end-of-life-and-bereavement.aspx>



Changes that can happen at the end of life



Choosing where to die



Getting ready to die



Who can help if you are dying



Spirituality and religion at the end of life



The end of life



Thinking about your funeral



What can help you feel better when someone dies

All the resources below are available on the IDS-TILDA website:

<https://www.tcd.ie/tcaid/about/easyreadmaterials.php>



Symptoms of Coronavirus >



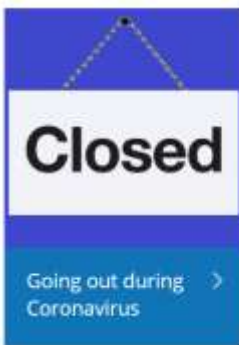
Protecting against Coronavirus >



Testing for Coronavirus >



Treatment for Coronavirus >



Going out during Coronavirus >



Health Promotion during Coronavirus >



Mental Health during Coronavirus >



## End of Life and Advance Care Plan supports



### Taking Control : My End of Life Support Plan

An easy read version for people with disabilities

[https://webarchive.nationalarchives.gov.uk/20160704190552/https://www.improvinghealthandlives.org.uk/securefiles/160704\\_2010//End%20of%20life%20plan%20FINAL.pdf](https://webarchive.nationalarchives.gov.uk/20160704190552/https://www.improvinghealthandlives.org.uk/securefiles/160704_2010//End%20of%20life%20plan%20FINAL.pdf)



Think Ahead form from the Irish Hospice Foundation

<https://hospicefoundation.ie/wp-content/uploads/2018/10/Think-Ahead-May-2018-Logo-Change-only.pdf>

An easy read version of this has developed by IDS –TILDA available on the webpage [www.tcd.ie/tcaid](http://www.tcd.ie/tcaid)

## Advocacy

A number of organisations are available in Ireland to provide advocacy support for people with disabilities:

**The National Advocacy Service** This service provides a free and independent representative advocacy service to adults with disabilities across Ireland.

[www.advocacy.ie](http://www.advocacy.ie) or by phone to 0761 07 3000

**SAGE Advocacy:** This service provide support for older people, vulnerable adults and healthcare patients [www.sageadvocacy.ie](http://www.sageadvocacy.ie)

**Inclusion Ireland** This organisation promotes advocacy for people with an intellectual disability, particularly self-advocacy. They provide an information and advice service by phone, post and through their website. [www.inclusionireland.ie](http://www.inclusionireland.ie)





## Supports for Staff

### The Palliative Hub: Webinars on Disability Services and COVID 19

The Palliative Hub has been developed by All Ireland Institute of Hospice and Palliative Care (AIHPC) with a number of palliative and hospice care stakeholders to act as a gateway to information and resources about palliative care on the island of Ireland.

Within the Hub there is a Professional Palliative Care section providing advice and guidance specifically for staff . A number of webinars have been held and are ongoing regarding people with disabilities and COVID-19. These are being made available to view on the webpage.

**Please note, that webinars will be removed from the site once guidance changes**

<http://www.professionalpalliativehub.com/covid-19/guidance-professionals>

<http://www.professionalpalliativehub.com/covid-19/project-echo-aiihpc-webinars-intellectual-disability-services>

### COVID 19: Assessment and recognition among people with intellectual disability

This is a new online education presentation available on the HSELand website that frontline staff working in disabilities may wish to complete. It will support staff to recognise the signs and symptoms of infection in a person with an intellectual disability and advice on practical steps to follow. It is for nursing and non-nursing staff including social care professionals.

The presentation has been developed by colleagues in the Intellectual Disability School of Nursing and Midwifery and the Trinity Centre for Ageing and Intellectual Disability in TCD working with staff in the HSE Nursing and Midwifery Planning & Development Unit (NMPDU).

## Practice guidelines for Social Care Staff



How social Care staff can support palliative and end of life care for people with learning disabilities

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/656271/Social\\_care\\_staff\\_supporting\\_palliative\\_and\\_end\\_of\\_life\\_care\\_in\\_learning\\_disabilities.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/656271/Social_care_staff_supporting_palliative_and_end_of_life_care_in_learning_disabilities.pdf)



How social care staff can use reasonable adjustments to support the health of people with learning disabilities

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/656271/Social\\_care\\_staff\\_supporting\\_palliative\\_and\\_end\\_of\\_life\\_care\\_in\\_learning\\_disabilities.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/656271/Social_care_staff_supporting_palliative_and_end_of_life_care_in_learning_disabilities.pdf)



How social care staff can recognise and manage pain in people with learning disabilities

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/656269/Social\\_care\\_staff\\_supporting\\_pain\\_management\\_in\\_learning\\_disabilities.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/656269/Social_care_staff_supporting_pain_management_in_learning_disabilities.pdf)

## Appendix 6: Enhanced Public Health Measures for COVID-19 Disease Management Long-term Residential Care (LTRC) and Home Support

The public health actions 1-6 aim to:

- Support the maintenance of residents in LTRCs unless there is clinical or other advantage
- Interrupt transmission of the disease and prevent onward spread in LTRC and the community.

### Agreed Public Health Actions LTRC facilities and Home Support

<p><b>No. 1 Strengthened HSE National and Regional Governance Structures</b></p> <ul style="list-style-type: none"> <li>• Establish a national and regional (CHO) LTRC COVID-19 Infection Prevention and Control (IPC) Teams with an allocated IPC Advisor to liaise with each LTRC and homecare provider</li> <li>• A local public health led Outbreak Control Team for each outbreak who will be responsible for data capture with support of LTRC via CRM system</li> <li>• Provision of updated guidance including LTRC specific admission and transfer guidance</li> <li>• Establish teams (per CHO), building on existing capacity where possible, to provide medical and nursing support to LTRCs</li> <li>• Establish capacity and provide for teams of last resort (crisis support team to go into individual LTRC facilities as required) to provide staffing for a short period of time to ensure service continuity</li> <li>• HIQA/MHC to risk rate all LTRC settings based on disease progression, environment and staff and liaise with national and regional governance structures and LTRCs as necessary in light of mitigating actions</li> </ul>
<p><b>No. 2 Transmission Risk Mitigation in suspected or COVID-19 positive settings LTRC and homecare staff</b></p> <ul style="list-style-type: none"> <li>• HSE to provide support for appropriate alternative residence and transport for staff living in congregated domestic living arrangements involving other LTRC settings/homecare staff</li> <li>• Minimise staff movement working across LTRCs</li> <li>• Agencies and LTRC/home support providers agree protocols to minimise staff movement across COVID-19 and non-COVID-19 LTRC settings/home support clients</li> </ul>
<p><b>No. 3 Staff Screening and Prioritisation for COVID-19 Testing</b></p> <ul style="list-style-type: none"> <li>• Prioritise LTRC staff/homecare staff for COVID-19 testing</li> <li>• Each LTRC should undertake active screening of all staff (Temperature checking twice a day)</li> </ul>
<p><b>No. 4 HSE Provision of PPE and Oxygen</b></p> <ul style="list-style-type: none"> <li>• Ensure PPE supply to LTRC settings and home support providers</li> <li>• Access to oxygen for LTRC settings</li> </ul>
<p><b>No. 5 Training</b></p> <ul style="list-style-type: none"> <li>• The HSE and LTRC settings support access to the provision of training for sufficient staff in IPC, use of PPE, use of oxygen, palliative care and end of life care, pronouncement of death</li> <li>• The HSE and home support providers support access to the provision of training for staff in IPC</li> </ul>
<p><b>No. 6 Facilities and Homecare Providers – Preparedness planning</b></p> <ul style="list-style-type: none"> <li>• Depending on size of LTRC or homecare provider designate a team or at least one full-time staff member as lead for COVID-19 preparedness and response</li> <li>• LTRC settings have COVID-19 preparedness plans in place to include planning for cohorting of patients (COVID-19 and non-COVID-19), enhanced IPC, staff training, establishing surge capacity, promoting resident and family communication, promoting advanced healthcare directives</li> </ul>



## Appendix 7: Extract from the HSE Operational Pathway of Care V1 . 19/03/2020

APPENDIX C: Care Pathway for suspected or confirmed COVID-19 during Mitigation Phase					
HOME	HSE LIVE COVID CONTACT CENTRE	GP & PRIMARY CARE	COMMUNITY ASSESSMENT HUB	INTERMEDIATE CARE CENTRE	ACUTE HOSPITAL ED/ ICU/ HDU
<p>Persons place of residence (including nursing home; residential homes; prisons etc.)</p> <p><b>Purpose:</b> Self-isolation for those with suspected COVID-19 or confirmed COVID - 19 with mild or moderate symptoms. Community supports may assist same vulnerable people at home.</p> <p><b>Supports Available:</b> HSE Online information; HSE Live COVID -19 contact centre; Enhanced community supports e.g. increased MOW, PHN's, community pharmacy, medication delivery; Voluntary community supports.</p> <p><b>Transport Arrangements:</b> Usual transport (e.g. family, taxis, community).</p> <p>NAS responsible for transporting to acute care settings only.</p>	<p>HSE Live telephone or online contact centre for those with suspected COVID-19.</p> <p><b>Entry Referral pathway:</b> Self-referral via telephone line or online (a carer, family member or concerned healthcare professional can do this also).</p> <p><b>Purpose:</b> Triage, advice and onward referral for people suspected to have COVID-19.</p> <p><b>Staffing:</b> Mixture of non-clinical call handlers and clinical staff. Tiered triage system.</p> <p><b>Exit Referral Pathway:</b> Three possible outcomes of triage: 1/ Self isolate at home with advice and/or supports; 2/ Referral to community hub for testing and assessment (via HSE Live case management system). 3/ Advising to go to ED and /or calling ambulance if acutely ill</p> <p><b>Transport Arrangements:</b> Getting to/from Community Hub: Usual transport (e.g. family, taxis, community transport).</p> <p>NAS responsible for transporting to acute care settings only.</p>	<p>GP/PCC to triage and provide advice to patients</p> <p><b>Purpose:</b> Via telephone assessment &amp; refer to Community Hub (register on HSE case management) or telephone support and advice for patients with suspected or confirmed COVID-19 in the community to avoid inpatient care.</p> <p><b>Staffing:</b> Existing team</p> <p><b>Exit Referral Pathway:</b> Three possible outcomes of triage: 1/ / Self isolate at home with advice and/or supports; 2/ Referral to community hub for testing and assessment (via HSE Live case management system). 3/ Advising to go to ED and /or calling ambulance if acutely ill</p> <p><b>Transport Arrangements:</b> Usual/ NAS responsible for transporting to acute care settings only.</p>	<p>Designated re-purposed Primary Care Centres with adequate environment for appropriate delivery of clinical care to support, access for patients, segregation and decontamination.</p> <p><b>Entry Referral pathway:</b> Referred via HSE Live case management system. GP's can also access this case management system and refer patients suspected of having COVID-19.</p> <p><b>Purpose:</b> In mitigation phase testing will no longer be carried out. Those who are symptomatic will be assumed to be positive for COVID-19. These community hubs will provide appropriate clinical assessment, treatment and triage for onward referral. Will provide out of hours service. Opening hours will scale up and down as required. Outreach service will also be provided for non-ambulatory vulnerable patients who are not able to access the community hub. DNA to community hub will trigger phonecall to patient and next of kin.</p> <p><b>Staffing:</b> GP's and nursing.</p> <p><b>Exit Referral Pathway:</b> Three possible outcomes of assessment determined by modified EWS: 1/ Treatment and advised to self-isolate at home with telephone follow-up. 2/ Referral to intermediate care centre facilitated by close working with bed management in intermediate care centre. 3/ Referral to ED for critically ill.</p> <p><b>Transport Arrangements:</b> Getting to/from Community Hub and to intermediate care centre: Usual transport (e.g. family, taxis, community). Feasibility of using voluntary and private ambulance should be explored.</p> <p>NAS responsible for transporting to acute care settings only.</p>	<p>Designated COVID-19 community hospitals / step down facilities/ community nursing units with piped oxygen facilities and 24 hour nursing care.*</p> <p><b>Entry Referral pathway:</b> Referred from community hub. Alternatively referred from acute hospital as step-down measure.</p> <p><b>Purpose:</b> Care of patients requiring 24 hour nursing care and/or oxygen who do not require critical care indicated by modified EWS score.</p> <p><b>Staffing?</b> Existing staffing in unit with additional supplementary redeployed staffing as required. 24 hour nursing care essential.</p> <p><b>Exit Referral Pathway:</b> 1/ Discharge home when appropriate 2/ Escalation of care to acute hospital through referral to ED (for critically ill)</p> <p><b>Transport Arrangements:</b> Getting to/ from intermediate care centre from community hub: People will use their normal method of transport (e.g. family, taxis, community transport). Feasibility of using voluntary and private ambulance should be explored if required.</p> <p>Transfer to intermediate care centre as stepdown from acute: National ambulance Service. Feasibility of using voluntary and private ambulance should be explored.</p> <p>Transfer to acute hospital: NAS responsible for transporting to acute hospital.</p> <p>* Strict cohorting and isolation of COVID-19 cases should apply regardless of whether designation of entire sites is realisable.</p>	<p>Designated COVID-19 Model 3 and 4 acute hospitals with ED, HDU, ICU. Designated COVID and non-COVID hospitals.*</p> <p><b>Entry Referral Pathway:</b> Referred from Community Hub or intermediate care centre or through ED (patient self-presentation or referral from HSE Live).</p> <p><b>Purpose:</b> Patients requiring critical acute care indicated by modified EWS score.</p> <p><b>Staffing?</b> Existing staffing in unit with additional supplementary redeployed staffing as required.</p> <p><b>Exit Referral Pathway:</b> 1/ Discharge home 2/ De-escalation of care to stepdown intermediate care centre.</p> <p><b>Transport Arrangements:</b> Getting to acute care: NAS responsible for transporting to acute care settings. Getting home from acute care: People will use their normal method of transport (e.g. family, taxis, community transport). Feasibility of using voluntary and private ambulance should be explored if required.</p> <p>Transfer to intermediate care centre as stepdown from acute via NAS. Feasibility of using voluntary and private ambulance should be explored.</p>

<https://hse.drsteevenslibrary.ie/c.php?g=679077&p=4841241>

**Non-Pharmacological Care in the Last Hours or Days of Life** One-pager guideline for the duration of Covid-19

Adherence to guideline recommendations will not ensure a successful outcome in every case. For more detailed guidance, suggest <https://www.palliativecareguidelines.scot.nhs.uk> AND/OR contact specialist palliative care team for advice. It is the responsibility of all professionals to exercise clinical judgement in the management of individual patients. In the event of a patient unexpectedly stabilising / improving, reconsider the diagnosis of 'dying'.

This guideline is for all healthcare professionals.

**SHIFT TO FOCUS ON COMFORT CARE:**

**General considerations**

Discontinue unnecessary prescriptions, monitoring activities, and procedures. Consider stopping anything that doesn't focus on comfort and alleviating symptoms/distress unless there is a good reason to continue it. Common areas that require review include:

- ✓ I/V fluids, antibiotics, s/c heparin, insulin, enteral nutrition & TPN.
- ✓ O<sub>2</sub> masks and nasal prongs unless clear symptom benefit.
- ✓ Stop blood and radiological tests.
- ✓ Stop monitoring vital signs including oxygen saturation, fluid balance etc.
- ✓ Deactivate ICDs and remove cardiac monitors.
- ✓ Ensure DNACPR order signed / EWS stopped.

**ENVIRONMENT:**

**General Physical environment:**

- ✓ Where possible a quiet, peaceful environment is preferable.
- ✓ Minimise loud noises and bright lights (delirium is not uncommon in last days/hours of life).

**Bedside environment:**

- ✓ Calm, reassuring bedside presence.
- ✓ Inform patient (even if unresponsive) who you are and what you are doing or about to do.

**PSYCHOLOGICAL / SPIRITUAL CARE:**

**Insight:**

- ✓ Where appropriate, patient insight should be assessed and fears / wishes explored.
- ✓ Consider if formal pastoral care support needed / rituals which are important to patient & family.

**PHYSICAL CARE:**

**Respiratory Secretions:**

- ✓ Explain to family & reassure that it may not represent discomfort.
- ✓ Re-positioning patient on side may help.
- ✓ Assess need for pharmacological intervention.
- ✓ Suctioning is rarely useful or indicated in last hours/days of life and has all the associated infection risks of an aerosol-generating procedure (AGP). It should be avoided where possible.
- ✓ For AGP and PPE guidance refer to <https://www.hpsc.ie>

**Bowel care:**

- ✓ Invasive procedures for bowel care rarely needed when imminently dying.

**Urinary care:**

- ✓ Catheterise if in urinary retention or incontinence likely to cause loss of skin integrity or aids the general comfort level of patient.

**Mouth care:**

- ✓ Ensure mouth and lips are clean and moist.
- ✓ Regularly moisten oral cavity with sips of water /water-based gel when able to swallow or with moist mouth sponge when unable.

**Food and fluid:**

- ✓ Continue to offer variety of soft foods / sips of water through teaspoon / straw while conscious, able to sit up, and as appropriate.
- ✓ Accept when patient unable/declines to take as this is natural part of dying. Never force.

**General comfort:**

- ✓ Repositioning, regular turning 2 – 4 hourly to prevent pressure sores.
- ✓ Regular skin and eye care.

**SOCIAL / FAMILY CARE** \* Physical presence will depend on infection control protocols

- ✓ Explain to family that death is approaching in sensitive yet clear way.
- ✓ Explain focus of care is on comfort and dignity.
- ✓ Explain the expected changes in physical and cognitive function as this will relieve distress for family.
- ✓ Check previous experiences and understanding of dying as it may allow you to correct misunderstandings.

**QUESTIONS FAMILY MEMBERS OFTEN ASK**

- ✓ How long has (s)he got?  
*"We can't be certain, but it's likely to be within a few hours or days at most. What would you like for her?"*
- ✓ Can (s)he still hear?  
*"We don't know for sure but if you would like to say something, now is the time"*
- ✓ How will you know if (s)he has pain?  
*"We will watch carefully for signs of distress. We will give whatever medication is needed to keep him/her pain free and comfortable"*
- ✓ Is (s)he dying of dehydration or starvation?  
*"At this time, all of the vital organs including his heart and kidneys are shutting down. His/her body cannot cope with food or fluid right now."*

**Version 6, 14.4.20**

Refer to <https://hse.drsteevenslibrary.ie> for most up to date information. This guidance document was developed by the National Palliative Care Clinical Programme in accordance with HPSC guidance, <https://www.hpsc.ie>



## Appendix 9: Practical advice for carers and families of a person at the end of life

### What you can do to practically care for someone who is in their last days and hours of life.

This guidance is for carers and family members to know what to expect and how to make the experience as comfortable as possible. Your healthcare team will advise you on the medications that can help with controlling symptoms experienced at the end of life.

#### 1. Breathlessness and cough

Breathlessness and cough can be a cause of agitation and distress and it can make it difficult to communicate. Don't expect the person to talk and give them time and space to respond. Reassure them that the unpleasant feeling will pass.

You can offer reassurance by talking calmly and opening a window to allow fresh air in.

If possible, sit the person up with pillows rather than lying flat as this can help the sensation of not being able to breathe.

Before someone dies their breathing often becomes noisy. Some people call this the 'death rattle'. Try not to be alarmed by this, it is normal. It is due to an accumulation of secretions and the muscles at the back of the throat relaxing. There are medicines that can be given to help dry up secretions if it is a problem.

#### 2. Pain

Some people may be in pain when they are dying. If they are less conscious they may grimace or groan to show this. There are medicines that can be given to ease pain.

Always check their positioning in bed to see if this can also help. They may be too weak to move and this can cause discomfort. Consider if they have any areas that are known to hurt, for example a bad back, and remember this when positioning them.

#### 3. Going to the toilet

Towards the end of life, a person may lose control of their bladder and bowel. Even though we expect someone to go to the toilet less as they eat and drink less, contact the health care team that is looking after them if they have not passed any urine for 12 hours or more as it can be uncomfortable.

Keep the person comfortable by regularly washing them and changing pads if they are wet or soiled.

#### 4. Agitation or restlessness

Some people can become agitated and appear distressed when they are dying. It can be frightening to look after someone who is restless. It's important to check if the cause is reversible like having a full bladder or bowel which can be reversed by using a catheter to drain the urine or medicines to open the bowels. Your health team can assess if this is necessary. Check if their pad is wet to see if they are passing urine or if they are opening their bowels. If it's not either of these things, there are things you can do and give to help. Try to reassure the person by talking to them calmly and sitting with them. Touch can be effective in doing this too. There are also medicines that can be given to help settle and relax someone.

#### 5. Feeling sick

Sometimes people can feel nauseated or sick when they are dying. If vomiting, and unable to sit up, turn the person on their side to protect their airway. There are medicines that can be given to help relieve this.