



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

How to support people with intellectual disabilities with a diagnosis of COVID-19

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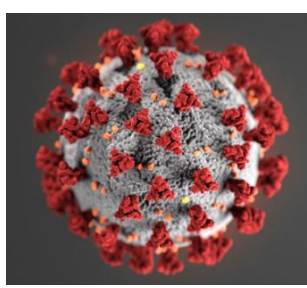
3 April 2020

www.tcd.ie/tcaid

@ageingwithID

#ageingwithID

Webinar Outline



The session will cover:

- Contextualizing COVID-19 and Intellectual Disability (ID)
- Advance Care Planning for people with ID in the context of COVID-19
- Transfer of people with ID with COVID-19 to the acute hospital: The pros and cons
- Palliative care approach for caring with multi-morbidities and COVID-19

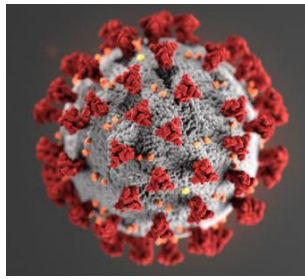
Applies to the Republic of Ireland – 3 April 2020



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About Coronavirus (COVID-19)



- Most people will experience mild to moderate respiratory illness, recovering without requiring special treatment.
- Older adults and people with underlying medical problems (diabetes, cardiovascular disease, chronic respiratory disease, cancer) are more likely to develop serious illness.
- Protect from infection by washing hands, not touching face and keeping physical distance.
- Virus spreads primarily through droplets of saliva or discharge from the nose, through coughing and sneezing.

National Intellectual Disability Database (NIDD), 2017

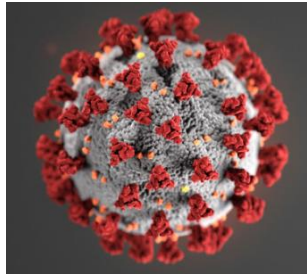
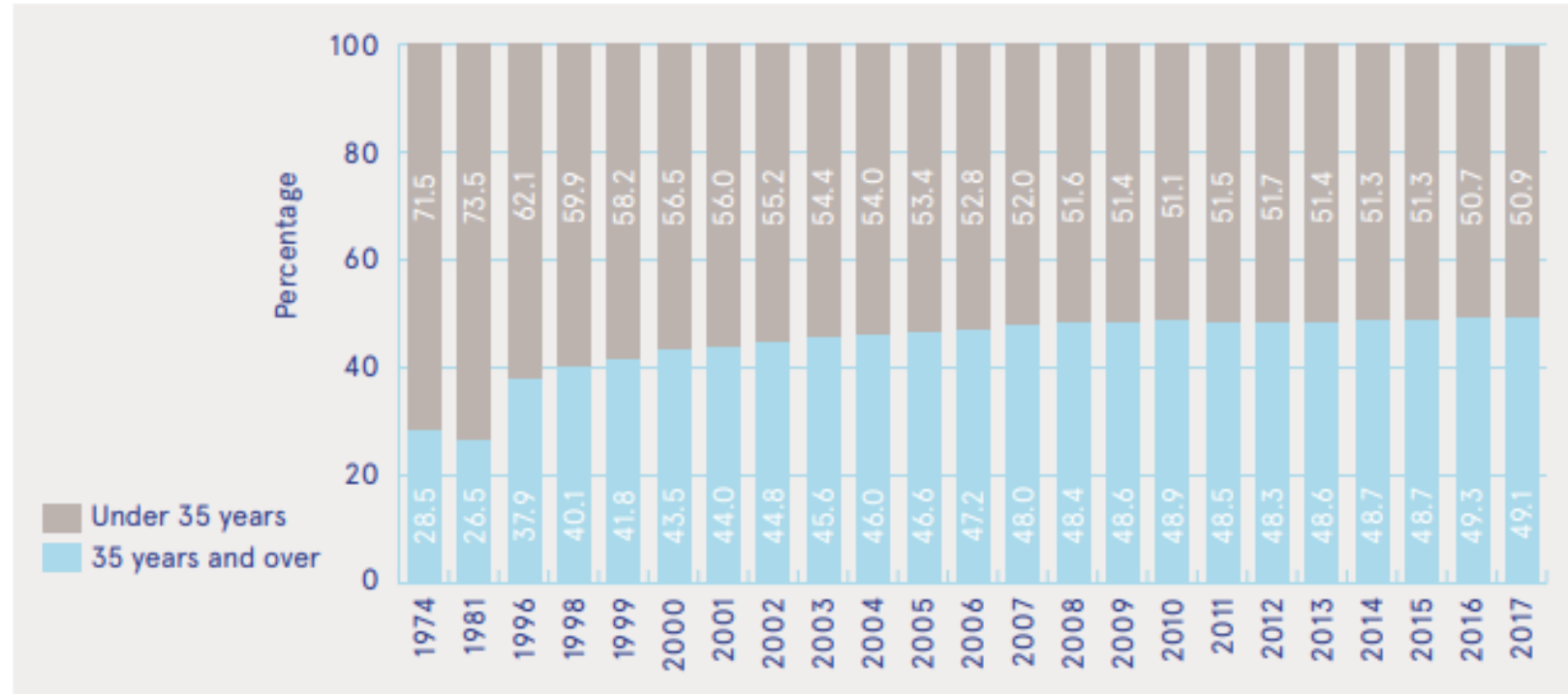


Figure 4. Percentage of people with moderate, severe or profound intellectual disability (combined), by age group 1974–2017, NIDD 2017

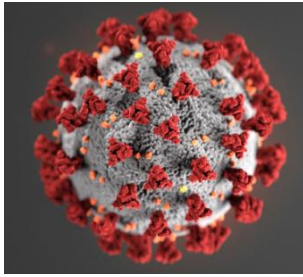
28,388 people registered on the NIDD, December 2017



Source:

https://www.hrb.ie/fileadmin/2._Plugin_related_files/Publications/2018_pubs/Disability/NIDD/NIDD_Annual_Report_2017.pdf

COVID-19: Are People with ID at Greater Risk?



- Risk is influenced by:
 - Age: 70+ years of age (even if you're fit and well)
 - Diabetes
 - Cardiovascular disease
 - Cancer
 - Immunotherapy
 - Severe respiratory conditions
 - Multiple chronic conditions (multi-morbidity)



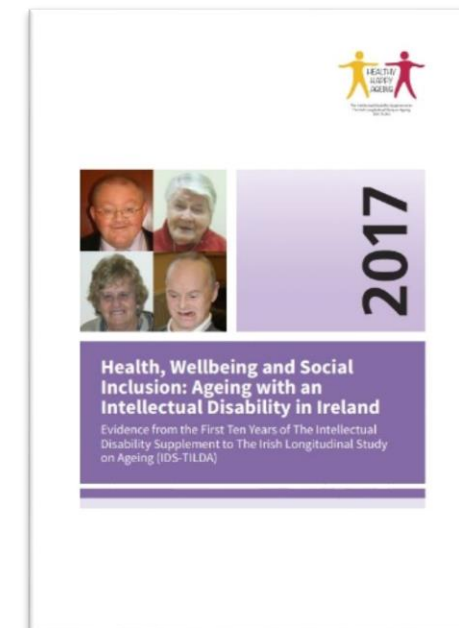
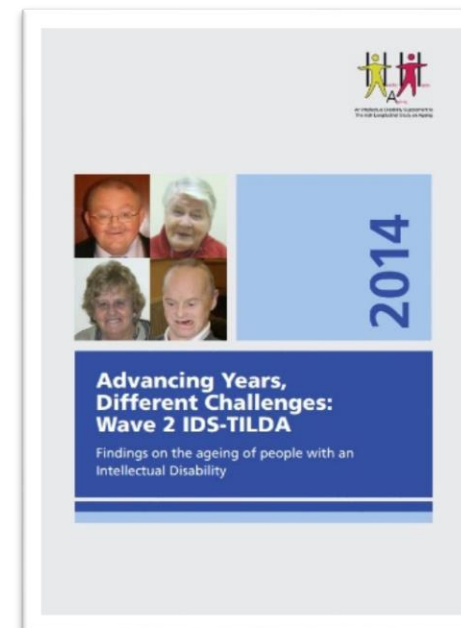
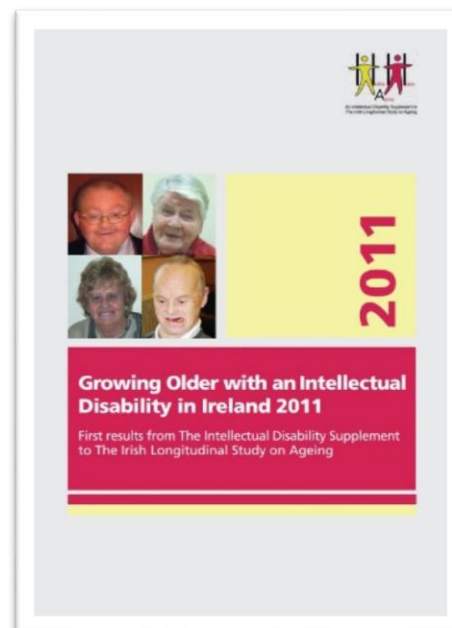
No evidence yet that having an intellectual disability is a risk factor.



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

Multi-morbidity in people with Intellectual Disability (ID): The potential impact of COVID-19

First nationally-representative longitudinal study on ageing with an intellectual disability
comparable to the general population

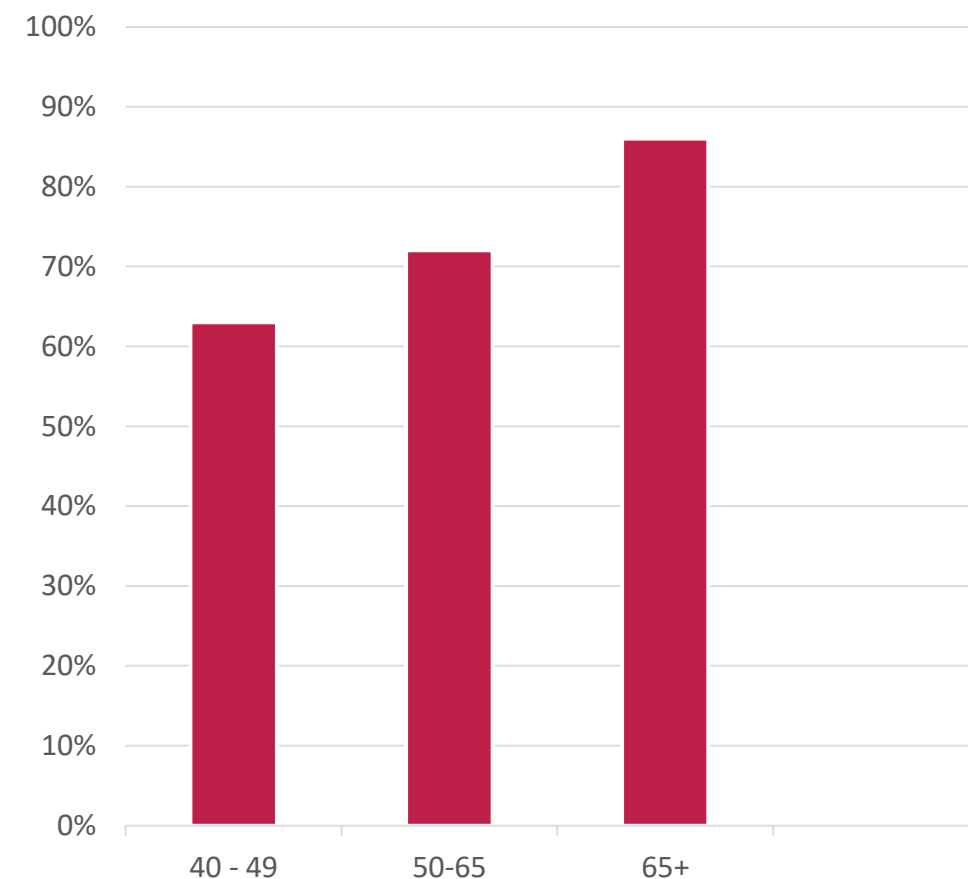




High prevalence of multimorbidity in adults with ID: *Across the entire adult life course*

- **IDS-TILDA identified multimorbidity for 71% of the older intellectual disability (ID) population in Ireland.**
 - This is higher than rates reported in the general older population (59%).
- **Multimorbidity starts earlier and increases with age:**
 - 63% in those aged 40–49 years
 - 72% in those aged 50–65 years
 - 86% in those aged 65 years and older

Multimorbidity in People with ID by Age





Contextualizing COVID-19: Multimorbidities

Intellectual Disability:

- Multimorbidity is highest among those with more profound levels of intellectual disability
- 30% of people with ID have epilepsy; **9.3% have diabetes (women 11%)**

Down syndrome:

- Having ≥ 4 chronic conditions is associated with Down syndrome
- Many have pre-existing cardiovascular and respiratory problems
- High Rates of dementia

Respiratory Disease:

- High rates of respiratory diseases in the ID population, particularly:
 - Pneumonias, including aspiration pneumonia
 - Dysphagia, problems with swallowing (common)
 - Even higher risk for people with severe to profound intellectual disabilities



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
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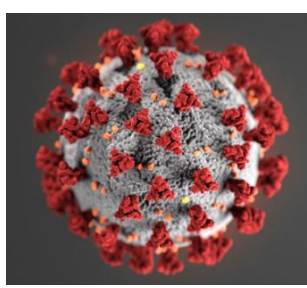
Contextualizing COVID-19: Psychological Health

Mental health concerns are significant for older people with ID:

- 52% reported a diagnosis of an emotional or mental health condition
- 15% of this population have anxiety
- The concept of social distancing may be difficult to understand and adhere to
- People with ID may not tolerate testing or interventions
- Testing does not affect treatment

The potential impact in terms of worry and disruption due to COVID-19 is a particular risk to the emotional, psychological and mental health well-being of this population.

COVID-19 Risks: The Focus is on Prevention



Coronavirus COVID-19

The Facts

Most at Risk

- Anyone who has been to an affected region in the last 14 days **AND** is experiencing symptoms
- Anyone who has been in close contact with a confirmed or probable case of COVID-19 (Coronavirus) in the last 14 days **AND** is experiencing symptoms

Prevention

Wash
your hands well and often to avoid contamination

Cover
your mouth and nose with a tissue or sleeve when coughing or sneezing and discard used tissue

Avoid
touching eyes, nose, or mouth with unwashed hands

Clean
and disinfect frequently touched objects and surfaces

Symptoms

• A Cough • Shortness of Breath • Breathing Difficulties • Fever (High Temperature)

Affected Regions

Check the list of affected regions on www.hse.ie

What to do if you are at risk

<p>I've been to an affected region in the last 14 days and</p> <p>I HAVE symptoms</p> <ol style="list-style-type: none"> 1. Stay away from other people 2. Phone your GP without delay 3. If you do not have a GP Phone HSE Line 1850 24 1850 <p>I DO NOT HAVE symptoms For advice visit www.hse.ie</p>	<p>I've been in close contact with a confirmed or probable case of COVID-19 (Coronavirus) in the last 14 days and</p> <p>I HAVE symptoms</p> <ol style="list-style-type: none"> 1. Stay away from other people 2. Phone your GP without delay 3. If you do not have a GP Phone HSE Line 1850 24 1850 <p>I DO NOT HAVE symptoms For advice visit www.hse.ie</p>	<p>For Daily Updates Visit www.gov.ie/health-covid-19 www.hse.ie</p>
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Protect yourself and others from getting sick

Wash your hands

- after coughing or sneezing
- when caring for the sick
- before and after you prepare food
- before eating
- after toilet use
- when hands are visibly dirty
- after touching cuts, blisters or any open sores
- you can use alcohol hand rub, if hands are not visibly dirty

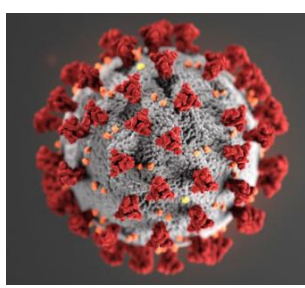
RESIST www.hse.ie/handhygiene



Preliminary Coronavirus Disease (COVID-19) Infection Prevention and Control Guidance including Outbreak Control in Residential Care Facilities (RCF) and Similar Units

v 1.1 30/03/2020

Should People with ID be Tested for COVID-19?



YES:

- The same guidance for testing should be used for people with ID as for everyone else
- The critical issues are whether there are symptoms and/or evidence that the person has been exposed to COVID-19
- The first step is to notify the person's GP and follow HSE/DOH guidelines
- **Testing and the results are of the utmost urgency** because social isolation can be especially challenging
- How many are displaying symptoms? Is a cluster forming?

If the individual displays symptoms and a test is requested by GP, the person should be isolated and their symptoms monitored, while awaiting testing.



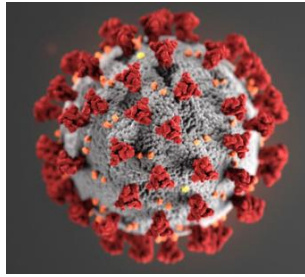
The Intellectual Disability Supplement to
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Contextualizing COVID-19: Managing Isolation

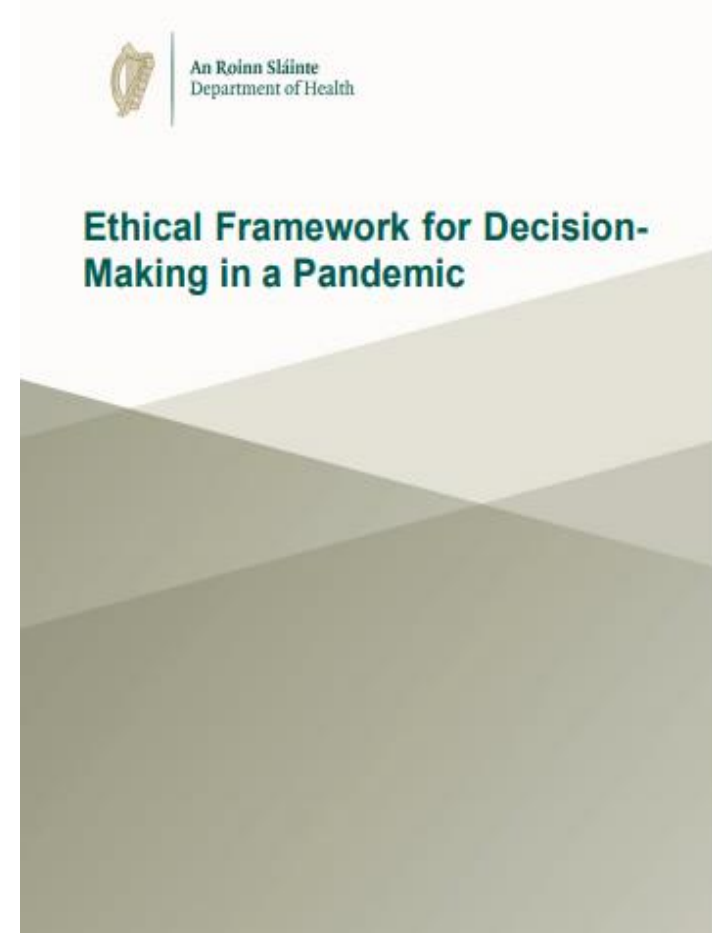
- **Is it possible in the current environment?**
 - Does the person have their own room?
 - Can this space be therapeutic (e.g. music, art, activities to keep the individual occupied)?
 - Is there a place for the person to wander or pace while in isolation?
 - Is there an enclosed garden or other facility that will be calming?
 - Is there another space within the same service environment better suited for isolation?
- **Are attempts at managing isolation putting others at risk?**
 - Are restrictions justified?
 - What are the least restrictive measures available to you?
 - Is medication required to manage distress/behaviour that challenge ?
 - Would the individual benefit from being moved to a different facility?

Webinar: Managing Isolating During COVID-19 Crisis: Practical Approaches – 9 April @ 10–11am

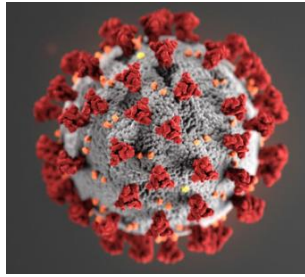
Diagnosed with COVID-19: An Ethical Framework for Decision-Making



- “Legitimate restrictions on an individual’s freedom can be justified in cases where exercising that freedom places other people at significant risk.
- In enacting any measure where personal freedom is limited, the least restrictive effective measure should be adopted’



COVID-19: Advance Care Planning – Why, When & How



Why:

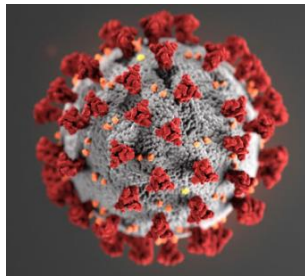
- COVID-19 Crisis
- Care in keeping with person's wishes (where possible)
- Make clear the pathway of care and pros/cons including transfer to the acute hospital
- Guide healthcare team and family when making decisions on patient's behalf

When:

- Prepare, prepare prepare: know who is at most risk
- Create Advance Care Plans for those most at risk – NOW!
- Provide a sensible approach for those **most at risk**
- **Know your population**

Webinar: Advance Care Planning & Anticipatory Prescribing During a Crisis – 7 April @ 11am -12pm

COVID-19: Advance Care Planning – How



- Use simple language and easy read materials
- Well documented: who, what discussed, the decisions, signed, dated
- Use accessible materials
- Time is not on our side
- **Get Advance Care Plans in place NOW**

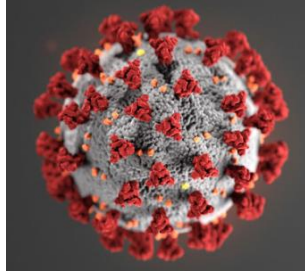
Future Care Road Map Planning Tool



<https://www.tcd.ie/tcaid/courses/knowledge.php>

Webinar: Advance Care Planning & Anticipatory Prescribing During a Crisis – 7 April @ 11am -12pm

COVID-19: Hospitalisation – The Pros and Cons



IRISH Mirror NEWS SPORT SHOWBIZ TV & FILM LIFESTYLE GAA MORE PREMIER LEAGUE

HOSPITAL TROLLEY CRISIS



Horrified wife slams University Hospital Limerick as she shares picture of 'cattle market' conditions

HOSPITAL TROLLEY CRISIS



Inside University Hospital Limerick's A&E - where dozens lay on trolleys waiting for beds

HOSPITAL TROLLEY CRISIS

Breaking

Last month saw 10,446 people on hospital trolleys

By Denise O'Donoghue

Irish Examiner

IRELAND WORLD SPORT BUSINESS VIEWS LIFE PROPERTY TECH SHOWBIZ MOTORS FARMING

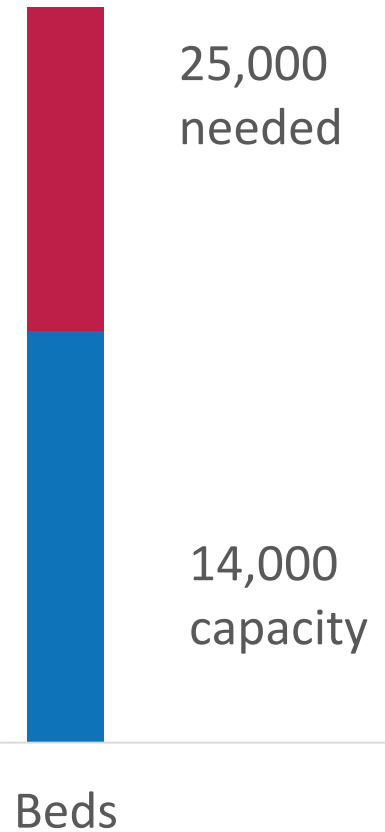
HOT TOPICS: WALKS NEWSPAPER DELIVERY GOVERNMENT FORMATION CORONAVIRUS PERSONAL INSIGHTS WAR OF INDEPENDENCE

HOME IRELAND

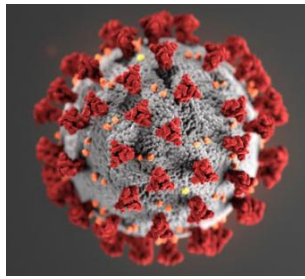
Nearly 1,300 on trolleys in UHL last month, latest

FOLLOW THE IRISH EXAMINER

Investors keep a keen eye on Cork city



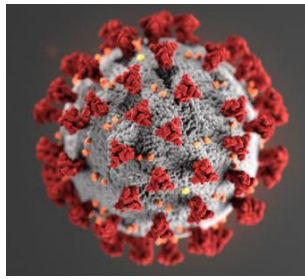
Diagnosed with COVID-19: Identifying the Best Care Pathway



- Remember, most people will have mild symptoms and/or recover from COVID-19
- A small percentage of people with COVID-19 will die and unfortunately this may include people with ID
- When people with ID have multiple health concerns, particularly with pre-existing, heart disease, diabetes respiratory problems, they are likely to have poorer outcomes from transfer to the acute hospital setting
- More likely benefit from and have better outcomes **if they are cared for in a familiar environment by familiar staff and we need to support and upskill staff to support their care**

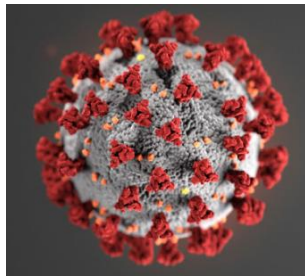
**Admission to the acute hospital is not the first line of defense,
it is the last line of defense.**

COVID-19: Hospitalisation



- There is no current specific treatment
- Does the individual require aggressive supportive care (ventilation/ICU) – burdensome, high mortality?
- Staff or family members will not be able to accompany the person – how will the person manage / cope?
- Will the last days in hospital isolation provide added stress to the individual and staff/family caregivers?
- Can the individual be properly cared for outside the acute setting?

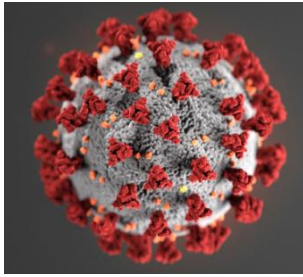
Diagnosed with COVID-19: Identifying the Best Care Pathway



- Others who become acutely unwell and prior to COVID-19 were deemed **fit and well**, may benefit from transfer to the acute hospital system and this care pathway must also be considered, and each person assessed on a case-by-case basis
- Regardless of having ID or not, people must be assessed as to whether critical care is needed
- The care pathway should be on the basis of multi-morbidity and the benefits and burdens of this intervention and **understood in the context of pre-existing intellectual impairment**

Multi-principled approach, including the patient's pre-morbid health status, their will and preferences (if known), the presence of co-morbidities, and overall health and general frailty.

COVID-19: What is the Best Environment for Care?

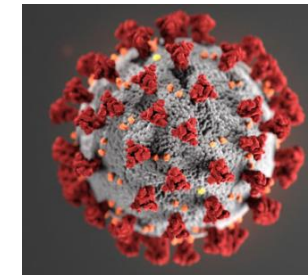


Main reasons why people might be transferred to hospital?

1. They would benefit from hospital care, prior to COVID-19 were fit and well, with no major health issues. The window is short - **Decline happens very quickly**, so people who would benefit should be moved early
2. They cannot be cared for where they are, do not have the staffing, skills and appropriate environment. Be honest and realistic about what you can and cannot do.

COVID-19: Providing Care Locally

Skill Staff to Recognise Symptoms

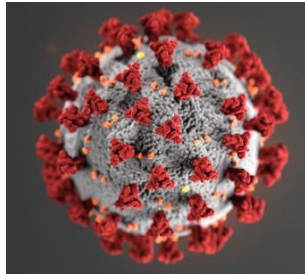


- **Altered Physical and Respiratory Status:**
 - New or worsened cough
 - New or worsening shortness of breath
 - New or increased sputum
 - **Alert for other new symptoms: clouding of urine, diarrhoea, GIT symptoms**
 - **Changes in body temperature****
- **Altered Mental Status:**
 - New signs or symptoms of increased confusion/delirium
 - Decreased level of consciousness
 - Inability to perform usual activities (due to mental status change)
 - New or worsening agitation
 - New or worsening delusions or hallucinations

The screenshot shows the HPSC website interface. At the top right, there are links for 'Data Privacy' and 'Cookie Policy', and a phone number '+353 1 8765300'. The main navigation bar includes 'NOTIFIABLE DISEASES', 'PUBLICATIONS', 'EPI-INSIGHT', 'TOPICS A-Z', and 'COVID-19 (NOVEL CORONAVIRUS)'. A search bar is also present. Below the navigation bar, there is a 'COVID-19 Information' section. On the left, a sidebar menu lists various topics, with 'PPE' highlighted. The main content area displays the title 'PPE' and the text: 'Current recommendations for the use of Personal Protective Equipment (PPE) in the management of suspected or confirmed COVID-19'. Below this, it states 'File Size: (660kb)' and 'Publication Date: 17 March 2020'. There is also a link to 'Preliminary Guidance on Facial Hair and Respiratory Protection in the Healthcare Setting in the context of COVID-19 and other pathogens transmitted by the same route'.

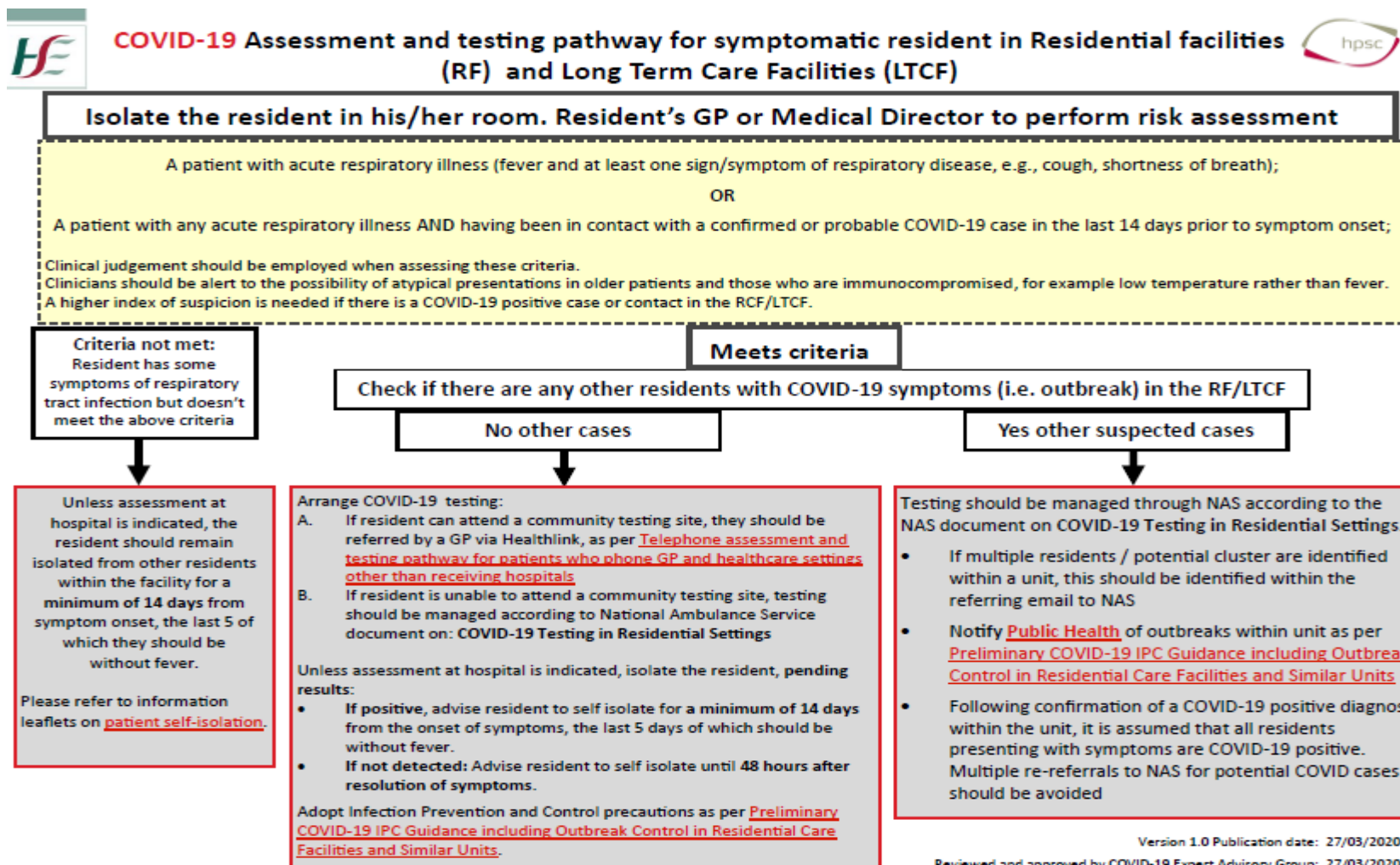
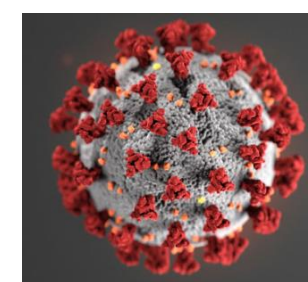
Review COVID-19 PPE guidelines as per current HPSC recommendations

COVID-19: Providing Care Locally

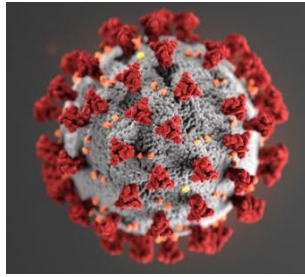


- Isolate the person, use PPE as recommended
- Assign staff to the isolation area
- Monitor vital signs and record
- Use escalation protocol AND clinical judgement
- Monitor Intake & Output as appropriate/per local policy
- Evaluate symptoms as appropriate for improvement or deterioration
- Refer to the individual's Advance Care Plan and anticipatory guidance
- Ensure supportive care for hypoxia, pain, fever or other symptoms
- Stay in regular contact with the person's family, advocate and caregivers
- Is tele-medicine an option for your service?
- Establish a relationship with your local hospital, don't wait to have a case

COVID-19 Risks: Assessment & Testing Pathway (HSE)



COVID-19: Providing Care Locally



Use the PINCH ME Tool:

P: PAIN

I: INFECTION

N: NUTRITION

C: CONSTIPATION COMMUNICATION

H: HYDRATION

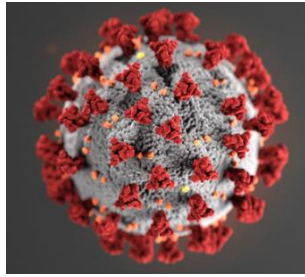
M: MEDICATION

E: ENVIRONNENT

ORAL CARE

SKIN CARE

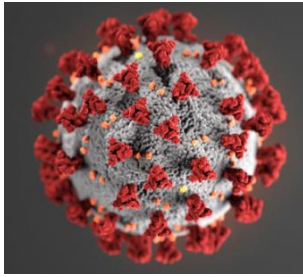
COVID-19: Providing Care Locally



- Have a plan and be proactive
- Engage with GPs (who are likely swamped)
- In groups homes and non-nursing settings, how will this be managed?
- Do you have the nursing support to provide palliative care? RNIDs
- Will you require nursing supports for symptom management (Sub-cuts / syringe drivers, etc.)
- Are you linked to acute hospital and palliative care

Webinar: Advance Care Planning & Anticipatory Prescribing During a Crisis – 7 April @ 11am -12pm

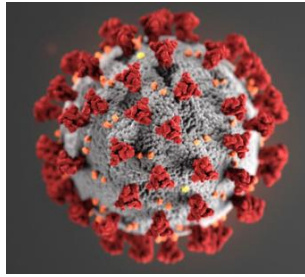
Advance Care Planning & Anticipatory Prescribing



- Individualised assessment always
- **HSE GUIDANCE**
- Last days of life: key symptoms and medications:
 - Dyspnoea/ breathlessness, cough common COVID 19 opioid (morphine sulphate), midazolam
 - Anxiety / agitated delirium: midazolam, levomepromazine / haloperidol
 - Pain: opioid (morphine sulphate)
 - Anti-secretory: hyoscine butylbromide (Buscopan) or glycopyrronium
 - Nausea / vomiting: levomepromazine / haloperidol
- Standard operation procedures need to be developed
- Safe custody requirements? Storage? Register books?
- Do you have the facilities required?
- Liaise with providers, who may have different ordering processes, limits, etc.

Webinar: Caring for the Person who is Dying - Upcoming

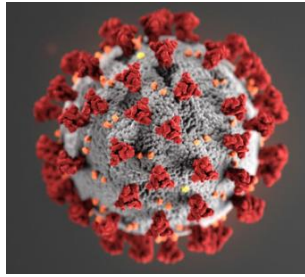
COVID-19: Difficult Time Caring for Peers, Staff and Families



- Be honest and open communications - What can you deliver and what can't you deliver?
- Do your own risk assessment and liaise with HIQA – This is a Public Health issue
- This is a difficult time for long standing relationships with staff, family and peers
- There may be multiple bereavements of residents and grief amongst staff and peers

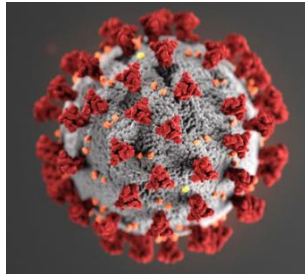
Webinar: Addressing Grief and Bereavement - Upcoming

COVID-19: Key Take-Home Messages



- Adhere to the HSE and DOH Guidelines
- Remember, most people will get a mild illness and will recover
- Advance Care Planning is more important than ever before: Plan, Plan, Plan
- Know your population and understand the best pathways to care: Prepare, Prepare, Prepare
- Hospitalisation: Understand the benefits and burdens – through honest reflection
- Look at developing an isolation zone within your service/organization
- You can provide individualised and good care in the person's home setting with the right supports
- Be realistic and honest about level of care you can and cannot support – Risk assessment

For More Information: Upcoming Webinars



Webinar: Advance Care Planning & Anticipatory Prescribing During a Crisis – 7 April @ 11am -12pm

Webinar: Managing Isolating During COVID-19 Crisis: Practical Approaches – 9 April @ 10–11am

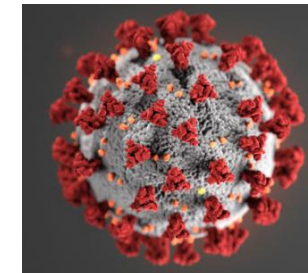
Webinar: Caring for the Person who is Dying - Upcoming

Webinar: Addressing Grief and Bereavement - Upcoming



Weekly Webinar Series

Certificate of Attendance



Services have been requesting a Certificate of Attendance.

If your organisation requires a certificate, please email:

Gavin Dann, Trinity Centre for Ageing and Intellectual Disability

dannng@tcd.ie

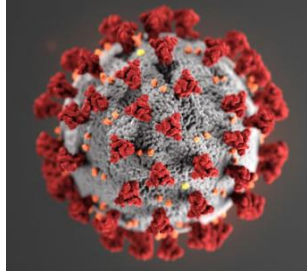
- Your Name
- Your Title
- The Organisation



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The Trinity Centre for Ageing and Intellectual Disability is an international and multi-disciplinary research centre examining key issues in ageing and the life course, informing policy and debate at the national and local level.

ABOUT

IDS-TILDA → Participant Involvement → Research Themes → Education and Knowledge Transfer → PPI Ignite@TCD →

COVID-19 Resources

Weekly Webinar Series

www.tcd.ie/tcaid



Resources

Trinity Centre for Ageing and Intellectual Disability: COVID Resources:

<https://www.tcd.ie/tcaid/about/covid19.php>

Advance Care Planning: <https://www.tcd.ie/tcaid/accessibleinformation>

The Palliative Hub: <http://www.thepalliativehub.com/>

HSE Toolbox Talks: End of life care, CPR and DNAR decisions

European Association of Palliative Care: www.eapcnet.eu

Communication around COVID-19: <https://www.vitaltalk.org/guides/covid-19-communication-skills/>

Coping with stress during COVID-19: <https://learn.nes.nhs.scot/741/quality-improvement-zone>

Easy Read Materials: <https://www.tcd.ie/tcaid/about/covid19.php>

IASSIDD website <https://www.iassidd.org/covid-19-resources/>



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Thank You

Professor Mary McCarron

Dr. Regina McQuillan

Dr. Jean Lane

Dr. John O Brien

Professor Sean Kennelly

Dr. Cathy Payne

3 April 2020

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