COVID-19 AND PEOPLE WITH INTELLECTUAL DISABILITY: GUIDANCE ON ADVANCE PLANNING FOR TREATMENT ESCALATION, CEILING OF CARE, PALLIATIVE CARE AND END OF LIFE
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AND END OF LIFE

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Introduction and Key Principles

1.1 People with an intellectual disability have premature mortality in comparison to the general population. CIPOLD (Confidential Inquiry into Premature Deaths of People with Learning Disabilities) found that for every one person in the general population who dies from an avoidable cause, 3 people with intellectual disability die. While people with intellectual disabilities have a number of inherent vulnerabilities (reviewed here), these physical health disparities are due to factors such as diagnostic overshadowing. In 2018/19, 41% of deaths were attributed to a respiratory cause. Dysphagia is under recognised and under reported; this alongside a higher prevalence of gastro-oesophageal reflux disease further impacts on state of nutrition and hydration which itself can be a prognostic factor for recovery from a significant illness.

1.2 There is considerable concern that during the COVID-19 pandemic, people with intellectual and other developmental disabilities will be denied access to the physical healthcare that they deserve. This is because historically, intellectual disability has been recorded as a rationale for a Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) order. This anxiety was exacerbated when the NICE rapid guidelines on access to critical care suggested the use of the Clinical Frailty Score (CFS), an instrument that would have systematically disadvantaged people with an intellectual disability.

1.3 Following high profile public campaigning from many stakeholders, and a proposed judicial review, NICE amended the guidelines to make clear that the CFS should not be applied to this group. However, family members remain concerned. Julie Newcombe, whose son Jamie has autism, is reported to have said: “The original guidance was quite simply frightening. For a long time now, many autistic and learning disabled people and their families have believed that they are treated as less than human, and it certainly felt as if the guidance was confirming just that. The hastily put together clarification is welcome, but I still wonder how that will translate on the ground given that attitudes in some areas are so entrenched.”

1.4 The NHS National Directors of Mental Health, Learning Disability, Autism and Primary Care have emphasised that decisions regarding appropriateness of admission to hospital for people with intellectual disabilities and/or autism are to be made on an individual basis and in consultation with their family and/or paid carers, taking into account the person’s usual physical health, the severity of any co-existing conditions and their frailty
at the time of examination. Treatment decisions should not be made on the basis of the presence of intellectual disability and / or autism alone.

1.5 The vast majority of people with intellectual disabilities within in-patient psychiatric units are there for assessment and treatment of their mental health or behaviour. The needs of this group are diverse, and no assumptions should be made regarding the physical health status of members of this population. There are a small number of inpatients who are ageing, with multiple frailties, in poor physical health. There may be a further group who while relatively healthy now, have a precipitous decline in their physical health following the experience of a virulent infection. The same applies to people with intellectual disabilities living in the community too.

1.6 In the context of COVID-19, while those with pre-existing health conditions have been specified as being at particularly high risk of a poor outcome following infection from this virus, people without pre-existing vulnerabilities and health conditions have died, and it is difficult to predict such deaths. Therefore, there is a need to consider carefully formulated end of life and palliative plans for these groups. This is to ensure that end of life is managed according to principles set out in the document ‘The route to success in end of life care - achieving quality for people with learning disabilities’:

- care being client-centred and integrated
- individuals being treated with dignity and respect
- people’s preferences being identified and respected and
- Care being provided after death.

**Referral to General Hospitals for Physical Healthcare**

1.7 There is clear guidance on the monitoring of suspected COVID-19 cases and the red flag symptoms (see Box 1). COVID 19 complications potentially requiring admission to Acute Hospital maybe as follows: Acute Severe (15%), Critical illness (5%), Classic Acute Respiratory Distress Syndrome or Atypical Viral Pneumonitis. Other organ Dysfunction may also occur (Renal, Liver and Cardiac dysrhythmias). COVID-19 is a new condition and the evidence base on this is evolving, there is no data available as yet on the outcomes for people with Intellectual Disabilities and how multiple morbidities play out in the development of complications as above.
1.8 In the context of this discussion, it is likely that issues of frailty and pre-morbid functioning (e.g. pre-COVID-19 infection) and diagnosis may arise. Clinicians in the community and in-patient psychiatry services should act as advocates for our patients receiving equitable access to physical health care (see Box 2).

1.9 While the recommendation from NICE’s COVID-19 rapid guidelines for critical care in adults clearly says that use of the Clinical Frailty score (CFS) on people with stable long-term disabilities such as intellectual disabilities or autism is not recommended, it also advises an individualised assessment in all cases where the CFS is not appropriate. The worry is that in busy general hospitals, in COVID-19 crisis, these caveats may not apply and people with intellectual disabilities will be denied the healthcare they need due to incorrect assumptions about their functional level. The concerns expressed regarding the CFS will also apply to instruments like WHO Performance Scores (originally used in cancer studies) and similar instruments that have not been validated in people with disabilities.

1.10 To minimise these risks and the health inequalities that can arise from using inappropriate tools, all in-patients on inpatient wards should have health passports and personalised COVID care plans (see Boxes 3 and 4) that set out their mental and physical co-morbidities, adaptive function levels and risks. We recommend that an updated HoNOS LD score is incorporated within that care plan. A significant increase in the individual specific score and overall score on HONOS LD would help to highlight deterioration of the patients mental and physical health comorbidities.

1.11 The above documents should guide discussions with those in the general hospital about the potential transfer to that setting of an unwell patient. Decisions about whether to accept admission to the general hospital, and access to critical care lie with the general hospital team, but clinicians from the in-patient psychiatric setting should provide the relevant information that allows ethical decision making (see Boxes 2, 3, 4).

The Need for Advance Care Plans, Treatment Escalation, Ceilings of Care, Palliative Care, End of Life and DNACPR discussions

1.12 As detailed in paragraph 1.5, these discussions are irrelevant for the overwhelming majority of in-patients in psychiatric wards as well as those living in the community. Intellectual disability is not a potentially fatal condition, and hence the default position
should be that people with that condition get access to the same level of physical healthcare as anyone else in the general population with reasonable adjustments as required by law. For those people, the ‘advance care planning’ for a potential COVID infection may be limited to the ‘COVID care plan’ that has been set out on Boxes 3 and 4.

1.13 In cases where it is relevant, discussions about treatment escalation, advance care plans, palliative care, end of life and DNACPR discussions need to happen within an ethical framework. This document provides further guidance to aid that process.

1.14 Timely, honest conversations about the person’s preferences and priorities, including advance decisions to refuse treatment, is part of advance care planning for anybody who has a progressive life-limiting illness. Barriers in the effective provision of palliative/end of life care in intellectual disability and autism: include; non recognition of end of life, poor communication, inequalities in accessing good care, staff awareness and non-collaborative working.

1.15 In the context of people with COVID-19, the first priority should be to treat in line with current guidance and refer to general hospitals as needed. It is possible though that COVID-19 may quickly exacerbate co-existing illness or further reduce physiological reserve and create a situation where the patient becomes rapidly sick and potentially unable to benefit from intrusive treatments. In such situations, honest conversations about goals of care and treatment escalation planning should be initiated as early as is practicable, so that a personalised care and support plan can be developed proactively. This will need to be revisited and revised as the situation changes. Families and those close to the person should be involved in these discussions as far as possible and in line with the person’s wishes. This is standard good practice in palliative and end of life care.

Assessment of Mental Capacity

1.16 Where someone has mental capacity to decide on medical treatment themselves, any decision to refuse treatment is for them alone. They may seek professional advice to aid that process.

1.17 Where someone lacks capacity, the Mental Capacity Act says professionals must make a decision in a person’s “Best Interests”. Assessing Best Interests involves ascertaining the
past views of the person and consulting family and any other significant people (through tele or video conferences if face to face contact is not possible).

**Stage 1: Starting this Conversation**

1.18 The Gold Standards Framework and Prognostic Indicator guidance detail three triggers that suggest a patient is nearing the end of life.
   1. The Surprise Question: ‘Would you be surprised if this patient were to die in the next [few months, weeks, days]’?
   2. General indicators of decline – deterioration in functional abilities, increasing need for care or choice for no further active care.
   3. Specific clinical indicators related to certain conditions.

1.19 Advance care planning should be considered when the answer to the “Surprise Question” is affirmative or when the other 2 of the 3 triggers in Stage 1 (above) are active. Advance Care Planning is a concept used not only in palliative care, but also for any kind of planning for the future. The process is designed to make clear a person’s wishes and will usually take place in the context of an anticipated deterioration in the individual’s condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.

**Stage 2: Treatment Escalation Plan Discussion**

1.20 Talking to patients and those close to them about prognosis, ceilings of treatment and possible end of life care is often challenging but, in the current COVID-19 outbreak, such conversations may become even more difficult, as health professionals may have to triage patients, often in emergency or urgent situations, and prioritise certain interventions. This is not only to ensure that those with potential to recover receive appropriate care, but also that those who are very unlikely to survive receive appropriate end of life care.

1.21 It is important that these discussions are done with empathy and sensitivity. It is recommended that the treating team (whether that is in primary or secondary care) identifies appropriate and willing staff members for these conversations: people who know the patient and their family well and have the essential skills to undertake the discussion.
**Treatment Escalation Plan**

1.22 To identify the wishes of the patient and their families and carers in case of a deterioration of the physical health due to COVID infection.

1.23 Where there is an advanced statement, advanced refusal of treatment or power of attorney with scope to make healthcare decisions, these will be followed unless the clinical situation appears to the clinician to be very different to any envisaged in the advance plans.

1.24 It is to provide guidance to the attending clinicians and should not replace clinical judgement.

**Guidance for Use**

1.25 Ideally, to be completed with the patient, families, carers and members of the MDT. In the context of the COVID crisis, teleconferencing/video conferencing discussion with the involved care team is recommended.

1.26 Once completed all staff caring for the patient should be made aware of the plan.

1.27 The Ceiling of Care/Treatment Escalation Plan form should be reviewed at the time of any relevant changes in physical or mental health.

**Patient Deterioration**

1.28 All staff should be aware of the Ceiling of Care/Treatment Escalation Plan Form. Any out of hours service i.e. on call doctor, Out of Hours GP or paramedic crew should also be made aware. They should also be aware that regardless of what has been expressed before, the patient is entitled to change his/her mind.

1.29 Patient should be examined and reviewed by attending doctor as, where possible, the decision to transfer to hospital should be discussed with the patient’s family.

1.30 If a transfer is required, a copy of the Ceiling of Care/Treatment Escalation Plan form should be sent, along with a covering letter if the patient has been reviewed by a doctor.

**Documentation**

1.31 The Ceiling of Care plan should cover the areas as set out in Box 4.
1.32 Some services may use a short Ceiling of Care /Treatment Escalation Plan Form that they develop.

**Stage 3: End of Life Plan**

1.33 Wherever possible, liaise with the local Palliative Care team for support.

**Step (i): Discussions as the End of Life Approaches**

1.34 Recognise when a patient’s signs and symptoms have increased or his or her condition has deteriorated. What are the symptoms noted, document and discuss with other professionals involved.

1.35 Ask yourself (again): “Would I be surprised if this patient were to die in the near future?”

1.36 Remember to take into account triggers such as recent changes in circumstances. Any new triggers noted in addition to COVID-19 infection, e.g. worsening of pre-existing physical or mental illness.

1.37 Identify whether it is appropriate to open a supportive discussion with the patient and/or their family about their wishes for end of life care and the best time or circumstances in which to do that. Use video conferencing or telephone to facilitate this conversation.

1.38 Consider carefully whether the individual wishes to have open discussions about prognosis and possible future care options.

1.39 Provide any relevant information that may be required by the patient or their family.

**Step (ii): Assessment, care planning and review**

1.40 Undertake a holistic assessment for end of life needs and preferences in partnership with your patient (if possible) and, where appropriate, their relatives and friends.

1.41 Assess and respond sensitively to the social, psychological and spiritual needs and wishes of a patient, as well as their physical care needs.

1.42 If necessary, support an assessment of your patient’s ability to make decisions about their care.

1.43 Identify, record and respond to your patient’s personal wishes and preferences about their future care and implement regular reviews (advance care planning) and verify this with their local GP if necessary/possible.
1.44 If requested, you should support a patient in the recording of an Advance Decision to Refuse Treatment document in an appropriate format.

1.45 Communicate information about personal wishes and preferences (with permission) to relevant people, e.g. the GP out-of-hours service.

**Step (iii): Co-ordination of Care**

1.46 Ensure local health and social care professionals are aware of those approaching the end of life. Some GP practices may be implementing an end of life care register specifically around COVID-19. Primary care have Gold Standards Framework registers of people who may die within the next year as part of standard practice. They have a depth of knowledge and excellent support mechanisms available via generic community nursing teams who usually deliver the actual end of life care (as well as specialist palliative care teams who are available for advice).

1.47 Ensure good communication systems are in place with all relevant services

1.48 Ensure key contacts are across the provider services, voluntary bodies and social care sectors are identified

1.49 Make sure there is a key worker within the home/unit for the individual approaching end of life, who can also act as the link between services

1.50 Ensure timely access to relevant equipment and any drugs that may be required is possible

1.51 Inform out-of-hours services of anticipated care needs.

1.52 Inform ambulance services of anticipated care needs.

**Step (iv): Delivery of High Quality End of Life Care and Maximising Comfort and Wellbeing**

1.53 Services should work to reduce fear and stigma associated with death and dying – a good death should be seen as the natural conclusion to a good life.

1.54 Each person is seen as an individual.

1.55 Support people with a intellectual disability to develop their awareness about death and dying

1.56 Involve families/friends/supporters and the person’s usual paid carers as partners in care (Ceiling of care)
1.57 Document and communicate updates with GP and care staff- (Ceiling of care/Treatment Escalation Plans

1.58 Support for those bereaved is an important part of palliative and end of life care.
   Establish contact with the local palliative care services.

1.59 Help the person to understand their illness and symptoms (MDT involvement).

1.60 Most people with intellectual disability will cope better with change if they understand what is happening.

1.61 Understanding about their illness can help reduce fear of the unknown.

1.62 Understanding the symptoms caused by illness can be important and helps the person report any changes in their symptoms / new symptom.

1.63 Understanding why the treatment is necessary and what the hoped outcome will be can help people cope with treatment.

1.64 Be creative in relieving psychological distress and improving wellbeing.

1.65 Identify distress by comparing the person’s current presentation to their baseline.

1.66 Carry out an effective and appropriate person centred pain assessment. Ways of assessing pain for the general population may need to be adapted for people with a learning disability where communicating pain verbally may be difficult.

**Step (v): Care in the Last Days of Life**

1.67 Be aware of the processes that occur during the last days of life and be alert to the possibility that on occasions the patient’s condition may improve.

1.68 Have open discussions with relatives, friends and other members of staff to ensure you all know what to expect during the last days of life, and offer support where needed.

1.69 Where possible, adhere to a patient’s stated wishes and preferences.

1.70 If a person lacks mental capacity, try to identify what they would take into account, if they could make their own decisions.

1.71 Where possible, have anticipatory prescribing systems in place or a system for rapid access to necessary medication.

1.72 Anticipate and accommodate religious, spiritual or cultural needs.

**Step (vi): Care after Death**

1.73 Respect individual faiths and beliefs and take steps to meet their requirements.
1.74 Be aware of verification and certification of death policies.
1.75 Provide appropriate information to relatives and carers about what to do after a death.
1.76 Offer information about bereavement support services if required.
1.77 Provide a comfortable environment in which staff and patients, can discuss or share their feelings.
1.78 Provide staff, patients and relatives with the opportunity for remembrance and to show their respect.

**BOX 1: COVID-19 RED FLAGS FOR PEOPLE WITH INTELLECTUAL DISABILITIES** Adapted from Greenhalgh et al. (2020).

The DISDAT tool can be used to monitor paid and distress and use of an instrument like NEWS is recommended to monitor physical health.

1. Severe shortness of breath at rest
2. Difficulty breathing
3. Pain or pressure in the chest (may clutch at the chest or show obvious signs of distress)
4. Onset of new confusion or worsening of challenging behaviour
5. Becoming difficult to rouse
6. Not eating or drinking
7. Little or no urine output
8. Cold clammy or pale mottled skin
9. Blue lips
10. Coughing up blood
11. Neck stiffness
12. Non blanching skin rash
13. Heart rate >100 with new confusion/ challenging behaviour
14. Respiratory rate > 20
15. Oxygen SATS ≤94%
16. Temperature >38°

If in doubt, discuss with a physician as per local arrangements.
**BOX 2: POINTS TO BE COVERED IN A REFERRAL DISCUSSION TO A GENERAL HOSPITAL**

1. Patient’s name, age, gender
2. Full diagnosis including physical and mental health (mention any conditions from Box 1 and Box 2)
3. Nature and duration of current symptoms and deterioration
4. Functional ability, capacity, and other relevant information form the COVID care plan and health passport (Clinicians have a responsibility to advocate for the person with an intellectual disability. A person with intellectual disability should not be denied care because of the disability).
5. If there are questions about instruments like the Clinical Frailty Score, please be aware [that NICE has made it clear that it should not be applied](#) to people with intellectual disability when making decisions on critical care. The same should apply to other instruments that do not take into account an individual’s pre-existing intellectual or developmental disability. NICE has stressed the need for an individualized assessment and that is what the referrer should help to provide.
BOX 3: COVID CARE PLAN: EXAMPLE (Patient with Capacity in an In-patient Setting)

Patient Name, Gender, Date of Birth: AB, Male, 01/01/1965

1. Mr AB is a 55-year-old Caucasian male who is an in-patient in a psychiatric unit for people with intellectual disability.
2. Diagnosis (mental health): Mild Intellectual Disability, Autistic Spectrum Disorder, Paranoid Schizophrenia
3. Diagnosis (physical health): Bronchial Asthma and early COPD, no hospitalizations for that, not on regular inhalers. He is an ex-smoker who is off cigarettes for over 5 years. He has obesity with a BMI of 31 (He is not morbidly obese).
4. His current medication is Depot Olanzapine and Tab Procyclidine. He is on PRN salbutamol inhalers that he usually does not like taking.
5. Prior to this admission, he was living in the community in supported accommodation and was healthy. At present, though not keen on exercise he has no active physical health symptoms. He carries out his daily activities with little help from others. (Can mention HONOS LD or equivalent scores, if appropriate).

Actions

1. To rate risk/ vulnerability level (Action: Doctor and MDT): Done. Mr AB is rated as a high risk/vulnerable patient (RAG rating: Red). This is firstly because he has a mild intellectual disability, bronchial asthma and early COPD, all conditions that comes within the category of the group at risk of severe illness from COVID-19. Secondly, he is also considered to be vulnerable to having mental health distress and relapse of his mental illness.
2. To give advice on social distancing and other COVID related precautions within the unit (Action: Nursing team): Done and is compliant
3. To offer a structured timetable of activities on the ward (Action: Nursing & Day Services): Done and attends about 60% of the time.
4. Capacity to consent assessment for physical healthcare (Action: Doctor): Done and on current evidence, does have the capacity to consent.
5. To give advice on procedures for isolation should that be needed (Action: Nursing team). Done and appears to understand, but insists he is fine.
6. To complete hospital passport (Action: Nursing & Doctor). Done
7. Communication passport (Action: Speech & Language Therapist): Done. Mr AB is capable of expressing his views clearly. He can be concrete in his understanding and needs reasonable adjustments in the way information is given to him.
8. To offer contact and support with the family (Action: Hospital social worker, Nursing): Is estranged from the family and hence has no direct contact with them. Does not want to see an advocate. Has a social worker who is in contact for care planning.
9. Mental Health (Action: Psychology, Doctor, Nursing): Updated formulation and associated additional treatments where practical to address any likely exacerbation of mental health symptoms and/or challenging behaviour (e.g. increase in compulsive checking, handwashing or rituals, increasing demand avoidance and associated aggression).
10. Mr AB does not have an ADRT (Advance Directive to Refuse Treatment). Discussed about ACP (Advance Care Planning) in the event of suspected COVID. While Mr AB has a intellectual disability, he has been living a fulfilling life and would like to be treated as any other member of the general public, a view that the treating team strongly supports. This is discussed in the weekly MDTs which has family/external professional participation. Mr AB does not have a condition that brings him in the shielding group. Mr AB is not a candidate for DNACPR in the current circumstances.
Patient name, Gender, Date of Birth: AB, male, 01/01/1965

1. Mr AB is a 55-year-old Caucasian male who is an in-patient in a psychiatric unit for people with intellectual disability.
2. Diagnosis (mental health): Moderate Intellectual Disability, Autistic Spectrum Disorder, Recurrent Depressive Disorder
3. Diagnosis (physical health): Bronchial Asthma, one hospitalization for that in the last year, on regular inhalers.
4. His current medication is Fluoxetine 20 mg/day.
5. Prior to this admission, he was living in the community in supported accommodation and was healthy (Can mention HONOS LD or equivalent scores, if appropriate).

Actions

1. To rate risk/ vulnerability level (Action: Doctor and MDT): Done. Mr AB is rated as a high risk/vulnerable patient (RAG rating: Red). This is firstly because he has a mild intellectual disability and bronchial asthma, all conditions that comes within the category of the group at risk of severe illness from COVID-19. Secondly, he is also considered to be vulnerable to having mental health distress and relapse of his mental illness.
2. To give advice on social distancing and other COVID related precautions within the unit (Action: Nursing team): Done, but doesn’t always understand it.
3. To offer a structured timetable of activities on the ward (Action: Nursing & Day Services): Done and attends about 60% of the time.
4. Capacity to consent assessment for physical healthcare (Action: Doctor): Done and on current evidence, this capacity is variable.
5. To give advice on procedures for isolation should that be needed (Action: Nursing team). Done, but doesn’t always understand it.
6. To complete hospital passport (Action: Nursing & Doctor). Done
7. Communication passport (Action: Speech & Language Therapist): Done. Mr AB can be concrete in his understanding and needs reasonable adjustments in the way information is given to him.
8. To offer contact and support with the family (Action: Hospital social worker, Nursing): No family contact other than a cousin who visits occasionally. Has a social worker who is in contact for care planning.
9. Mental Health (Action: Psychology, Doctor, Nursing): Updated formulation and associated additional treatments where practical to address any likely exacerbation of mental health symptoms and/or challenging behaviour (e.g. increase in compulsive checking, handwashing or rituals, increasing demand avoidance and associated aggression).
10. Mr AB does not have an ADRT (Advance Directive to Refuse Treatment). He lacks the capacity to have a meaningful discussion about ACP (Advance Care Planning) in the event of suspected COVID. While the patient has a intellectual disability, he has been living a fulfilling life. There have been discussions about this in the weekly MDTs which has family/ external professional participation. The considered view is that in the event of a COVID infection, he should be treated as any other member of the general public. Mr AB does not have a condition that brings him in the shielding group. Mr AB is not a candidate for DNACPR in the current circumstances"
BOX 5: TOPICS TO BE INCLUDED WITHIN A TREATMENT ESCALATION, CEILING OF CARE, PALLIATIVE CARE AND END OF LIFE PLAN

1. Name, Date of Birth, Address.

2. Information about whether there is an existing current advance plan, such as an Advance Statement, Advance Decision of Refusal of Treatment, or Lasting Power of Attorney for Health/Welfare or Deputy.

3. Details pertaining to an assessment of Mental Capacity. Remember that this is decision specific, and capacity is assumed as default position.

4. Record any discussions with individuals, their family members, carers, friends and others.

5. Record any decisions about cardiopulmonary resuscitation. If a decision is made to not attempt cardiopulmonary resuscitation, then a Do Not Attempt Resuscitation or Cardiopulmonary Resuscitation form must be completed.

6. Record information about the ceiling of care. This could be Full Active Care which would be transfer to general hospital, or Palliative/End of Life Care which would not be transfer to the general hospital and input from palliative care services would be needed working with generic community nursing teams who provide end of life care. Some community-based residential services are not equipped to provide a full range of palliative care services which may necessitate transfer to hospital or a palliative care unit, especially if there is treatment available which significantly improve pain, discomfort or dignity. This could also be Care within an Existing Inpatient Psychiatric Ward environment if that is where the individual is currently located. This would not involve transfer to a general hospital unless there is treatment which would significantly improve pain, discomfort or dignity which cannot be provided within the psychiatric hospital.

7. Include information about prescribing antibiotics including whether they require oral only, and whether intravenous antibiotics may be appropriate, or no further antibiotics are to be given (unless required for symptom control).

8. Food and fluids including whether intravenous fluids are not appropriate, or a percutaneous endoscopic gastrostomy tube is appropriate. Consider wider issues about inability to swallow and whether this is part of the progression of the acquired disease (e.g.: dementia).
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