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Office for People With Developmental Disabilities

# Questions for Death Investigations

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Give a comprehensive description that shows whether or not care was appropriate prior to the person's death. The investigation needs to state in a **clear way** what kind of care the individual received and describe whether the interventions were or were not timely, per training, procedure, and/or service plans.

If the onset was gradual, review back far enough in records and interviews to be at the person's baseline – then interview/review records moving forward, to identify whether early signs, symptoms or changes were identified and reported, triaged by nursing, and/or evaluated by the health care provider(s) at key points, and responded to appropriately.

If law enforcement or the Justice Center is conducting an investigation related to the death of the individual, the agency should inquire as to actions, if any, it may take to complete the death investigation. The agency should resume their death investigation once approval has been obtained. The death investigation is always the responsibility of the agency.

## Here are some key questions investigators should ask:

- What were the diagnoses prior to this acute issue/illness? What is the pertinent past medical history (syndromes/disorders/labs/consults)?

- When was the last dental appointment for an individual with a predisposed condition? Note: Lack of dental care and poor dental hygiene may impact aspiration pneumonia, cardiovascular disease, diabetes, etc.

- Was the preventative health care current and adequate? Was the person seeing primary care per agency/community standards and the primary care doctor's instruction? Specialist care, per recommendations? When was the last lab work, check for medication levels? Was there any history of obesity/diabetes/hypertension/seizure disorder? Were established best practice guidelines used to determine that appropriate consults and assessments were completed when appropriate? If so, what guidelines?

- Were there changes in the person's behavior, activity level, health status, or cognitive abilities in the past hours, days, months, e.g. unusually agitated, progressive muscle weakness, more confused?

- How and when was the acute issue identified? Could it have been identified/reported earlier? Was it related to a prior diagnosis?

- What are the pertinent agency policies and procedures? Were they followed or not?

- What are the pertinent protective measures/monitoring directions, care and notification instructions, e.g. Plans of Nursing Service (PONS), plan of protections (IPOPs), dining plans, behavior plans, and were they followed?

- What is the pertinent staff training? Were staff involved trained? Was it up-to-date? Were the actions in line with training?

- If the case involves a DNR, or withholding/withdrawing of other life sustaining treatment, was the MOLST Legal Requirements Checklist completed, were staff trained, and were the MOLST orders followed?
  *see http://www.opwdd.ny.gov/opwdd_resources/information_for_clinicians/MOLST

- Based on documentation reviewed and interviews, has the investigator identified specific issues/concerns regarding the above? Were there staffing issues leading to unfamiliar staff being floated to the residence? Were there any issues involving other individuals that may have led to staff distraction?

- Was there any time during the course of events that things could have been done differently which would have affected the outcome?

- Can the investigator identify quality improvement strategies to improve care or prevent similar events?

- Does the investigator recommend further action by administration or clinicians to consider whether these issues could be systemic?

- Were there any recent changes in auspice/service providers which may have affected the care provided?

- Did the individual have any history of behaviors that may have affected staffs' ability to identify symptoms of illness (individual reporting illness/shallow breathing for attention seeking purposes, etc.)?

- Were there any relevant OPWDD nursing policy/guidance (https://opwdd.ny.gov/opwdd_careers_training/training_opportunities/resources_for_learners/Nursing_in_OPWDD) or Administrative Directive memorandums (https://opwdd.ny.gov/opwdd_regulations_guidance/adm_memoranda) that should have been followed?

## Investigative questions for specific types of deaths (select as appropriate)

### Fatal Choking Event – Obstructed Airway Causing Death by Asphyxia.

Risks

- Was the individual on any medications that could cause drowsiness/depressed breathing? Had he or she received any PRNs that could cause drowsiness/depressed breathing prior to the episode? Did the individual receive sedation related to a medical procedure?

- Were there previous episodes of choking? How many? Circumstances?
- Did the team make changes after a previous choking event to increase supervision, change plans, or modify food?
- Were there any previous swallowing evaluations and when were they?
- Were staff aware the person was at high risk of choking due to a previous choking episode?
- Was there a known mechanical swallowing risk? Were staff aware of the risks/ plan? Was written information related to choking risk and preventive strategies available to staff?
- Was there a known behavior of food-seeking, taking, or hiding? Dining behavior risk e.g. food-stuffing, talking while eating, or rapid eating?
- Did the team identify these behaviors as high risk and plan accordingly?
- Was food taking/sneaking/stealing managed? Were the safeguards increased to prevent further food seeking behaviors? Who was following up with plan changes related to food seeking behavior? Was this well-defined and effective?
- Did the individual have a history of Pica? Severity? Previous episodes? Did plan address Pica as a choking risk?
- Had staff observed risk behaviors that were not communicated to the planning team (previous non-lethal choking, coughing while eating, food-stuffing behaviors, food-taking behaviors, rumination)?
- If the individual required pacing while dining, was this incorporated into a dining plan?

<u>Plan and Staff Actions</u>

- What were the safeguards for safe dining e.g. consistency, support, storage, positioning? Were they followed?
- What was the individual's level of supervision? Was it provided? Was it realistic given other staff duties?
- Was there a specific plan? Was it communicated? Available?
- What is the policy for training? Were staff trained per policy (classroom and IPOP)? Can they describe the plan? Did the choking occur off-site or in a non-traditional dining setting (e.g. at the mall, picnic, or bedroom)? Were plans and

staff directions clear on how to manage such situations? Did staff follow plans in the non-traditional/community setting?

**Bowel Obstruction – Most commonly, bowel obstruction is due to severe, unresolved constipation, foreign-body obstruction, obstruction due to cancerous mass, volvulus "twisted bowel", or Ileus (no peristaltic movement of the bowel).**

Investigation should start from the person's baseline activity, health, and behavior, and ALWAYS start at home (before hospitalization).

- Any history of constipation/small bowel obstruction?

- Was there a written bowel management regimen? What was the bowel management regimen e.g. routine medications, PRN medications? Did PRN orders have direction on what to do if not effective? Did staff follow orders/report as directed? Was there evidence of MD or RN oversight of implementation?

- Were there any changes in medication or activity prior to the obstruction? Did the person start a narcotic pain medication? Start or increase another medication that can cause constipation? Stop/reduce a bowel medication?

- Was there bowel tracking? What did the bowel records show? Who reviewed the bowel records (MD, RN)? Were problems identified and changes considered in a timely fashion?

- Did the person have an injury or illness that impaired mobility? Exhibit any behavior or pain?

- Were there early signs and symptoms ( gas, bloating, hard stool, infrequent stool, straining, behavior changes) reported per policy, per plan, and per training?

- Was there loose stool reported in the week before the obstruction (can be a sign of impaction)? Was this reported? Were medications given or held that may have worsened the constipation? Did staff decide this independently, or was it with nursing direction?

- Was there a PONS? Were staff trained on the PONS? Did the plan address refusal of food, vomiting, and/or distended abdomen?

**Aspiration Pneumonia (Individuals who are elderly are at a higher risk)**

- Any medical condition that would predispose someone to aspiration?

- When was the last swallowing evaluation?

- Any food seeking behavior?
- Any history of aspiration? Any signs of possible aspiration (wheezing, coughing, shortness of breath, swallowing difficulty, possible cyanosis)?
- Was staff training provided on aspiration and signs and symptoms?
- Was there a PONS in place for those who have a condition that would predispose the individual to aspiration pneumonia (dysphagia, dementia)? Did the PONS address positioning and food consistency? Did staff understand and follow dining/feeding requirements?
- When was medical treatment sought?
- Did the individual receive any medications that could cause drowsiness?
- Was there an order for Head of Bed (HOB) elevation? If so, was it followed and documented?

**Seizure**

- Seizure frequency? History vs. acute onset?
- Was there an emergency protocol for infrequent or status epilepsy?
- When was the last neurology appointment? Were appointments attended per practitioner's recommendations?
- Were there any recent medication changes?
- When was the last blood level done for medication levels?
- Was there any illness or infection at the time of seizure?

**Septicemia, sepsis or Septic Shock**

**Sepsis (septicemia) can result from an infection somewhere in the body including infections of the skin, lungs, urinary tract, or abdomen (such as appendicitis). Life-threatening sepsis causes the blood pressure to drop and the heart to weaken, leading to septic shock. Once this happens, multiple organs may quickly fail and the patient can die. (CDC.gov, 2014)**

Most often people are in the hospital when they die from sepsis. Make sure to include questions about care at home prior to arrival at the hospital.

For the time at home:

- Was there a diagnosed infection under treatment at home?
- Who was the doctor/provider managing the illness? Was there a plan for provider follow-up?
- What was the infection? What was the treatment?
- Was nursing and/or the medical practitioner advised of changes in the individual?
- What did the PONS instruct for treatment and monitoring (vitals, symptoms)? What were the directions for calling a nurse? 911? Was the plan clear? If fluids are to be given, how much? If monitoring urine output – report what amount, or qualities? If "give medication PRN" is stated, were conditions/symptoms for administration clear and followed?
- Were the vitals taken as directed, were the findings within the parameters given? Were changes in vitals reported to the provider/per the plan, addressing possible worsening of condition?
- Were the medications given as ordered? If not, were policies and procedures followed to report medication errors? Were missed doses reviewed with the provider? Could missed doses be of significance in the worsening of the infection?
- Did staff report to nursing when a PRN was given? What was follow up time to PRN given?
- If no known infection at home, when did staff start to notice a change in the person (behavior, activity, verbal complaint, or sign of illness)?
- Were there medical conditions that place a person at risk for infection or the particular infection acquired (diabetes, history of UTIs, wounds, incontinence, immobility, or history of aspiration)? Were the risks addressed?
- What were the symptoms which sent the person to the hospital? How quickly did they appear? Did staff report per policy, per plans, and per training?

**Falls**

- Were vital signs taken after the fall (this may determine hypotension)?
- Did the individual have any history of seizures or other neurological disorder?

- Did the individual have a history of falls?
- Was a fall risk assessment completed?
- Is it known whether the individual lost consciousness prior to the fall?
- Was there a PONS regarding falling?
- Had the individual received sedative medication prior to the fall?
- Was the fall observed? If the fall was not observed, did staff move the individual?
- Is it known whether the individual hit his or her head during the fall?
- Did the individual require staff assistance to stand, to walk? Was it provided?
- Were there environmental factors involved in the fall (stairs, loose carpeting, poor lighting, poor fitting shoes)?
- Did the individual use any assistive devices (gait belt, walker, etc.)? Was the device being used at the time of the fall?

**Questions for Individuals with particular medical histories/diagnoses:**

**Down Syndrome**

- Did the individual have a cardiac history?
- Did have neurological issues (disposed to early onset dementia/Alzheimer's)?

**Cardiac:**

- When was his or her last consultation with a cardiologist? Were appointments attended per practitioner's recommendations?
- Was the individual receiving medications related to the cardiac diagnosis and were there any changes?
- When was his or her last EKG? Did it occur per practitioner's recommendations?
- When was his or her last lab work (especially if acute event)? Did it occur per practitioner's recommendations?

- Was there a PONS for this diagnosis?
- How frequent were the individual's vital signs taken? Did a plan include identified ranges and were there any outliers? Was the PONS followed?
- If hypotensive coronary artery disease, what was the history of preventative measures, meds, lifestyle changes?

**Gastro Intestinal Diagnosis:**

- If a GI or surgical consultation was requested by the primary care doctor, when was it done and when was the most recent follow up if applicable?
- If the individual is between age 50 and 75, when was his or her last screening for colon cancer and what were the results? Did it occur per practitioner's recommendation?
- Was there a bowel monitoring plan?
- Was the individual receiving any medications related to this diagnosis?
- Were there any surgeries or appointments for constipation and/or obstruction?
- Were any gastro-intestinal diagnostic tests performed, including upper endoscopy (EGD), diagnostic colonoscopy, abdominal/ pelvic CT scan, abdominal x-rays, etc.?
- Did the individual receive any blood thinners (if GI bleed)?
- Were staff trained on relevant signs/symptoms?
- Was there a nursing care plan regarding this diagnosis?

**Gynecological:**

- When was the last GYN consult? Were appointments attended per practitioner's recommendations?
- Were there any diagnoses requiring follow up?
- Was the individual on any contraception?
- Were there any surgeries and follow up?
- Was there a nursing care plan?

**Neurology Disorder:**

- Dysphagia, dementia, seizures can happen with neurological diagnosis.
- When was the last consultation? Were appointments attended per practitioner's recommendations?
- Did follow up occur per recommendations?
- If seizures occurred, what was the frequency?
- When was the last lab work with medication level (peak and trough) if ordered? Did it occur per practitioner's recommendation?
- If the individual was diagnosed with dysphagia, when was the last swallowing evaluation?
- Was there a PONS for dysphagia/dementia/seizures?

**Listed below are some situations which can influence the focus of questions. They are not diseases or causes of death, but rather circumstances. Use these questions as appropriate.**

**Transfer of Oversight/Service Provision Between Programs**

- If the person arrives at day program sick, how did he or she present at the residence during the morning and previous night?
- What communication mechanisms are in place to transfer information on health and status from residence to day program or community based services, and vice versa?
- Did necessary communication occur?

**Sudden Changes**

If the change was reported to you as sudden or within 24-hours of an ER or hospital admission, review notes a few days back and consider interviews regarding staff observations during that time.

- Any changes in health status?

- Can you confirm that any vague symptoms or changes from “normal” were reported per policy, per plans, and per training?
- Any changes in medications prior to the acute incident?
- Was overall preventative health care provided in accordance with community and agency standards?
- What were the prior diagnoses? Any predispositions?
- Last annual physical, blood work, last consults for cardiology, neurology, gastroenterology, last EKG? If diagnosed with seizures, frequency?
- What PONS were in effect and were staff trained?

**Hospital Deaths**

If death occurs in the hospital – the following are general questions to consider:

- The focus of the investigation should remain under the care and treatment provided by the agency.
- What occurrence brought the individual to the hospital? What was the diagnosis at admission?
- What communication occurred between OPWDD service provider and hospital? Was the agency RN involved in communications?
- Did the individual require agency staff to support him or her in the hospital? Did this occur per the plan?
- What was the course of stay and progression of disease?
- Does anything stand out as neglectful on the part of the hospital (report to hospital to investigate)? On the agency’s part?
- Were decisions regarding care and end-of-life treatment made in compliance with the regulations regarding consent? Were the decisions in the individual’s best interest? See End of Life Planning/MOLST, below

**Expected Deaths, end-stage disease**

With certain conditions like Alzheimer’s, COPD, or heart failure, symptoms are expected to worsen over time and death becomes increasingly likely. These may be the key questions to focus on in these circumstances:

- Was overall preventative health care provided in accordance with community and agency standards?

- What was the diagnosis? What was the latest prognosis?

- Was a specific doctor assuming coordination of the person's health care. Which doctor was coordinating the health care? When was the last visit to this doctor?

- Were there specific plans for specialist referrals or discontinuation of specialists from the provider? Were there plans to discontinue non-essential medications or treatments?

- Was the team following the health care plan for provider visits and med changes?

- Was end-of-life planning considered? Was it implemented?

- What were the PONS in place at the time? Were staff trained? Were the plans followed?

- Was there anything done or not done which would have accelerated death?

- Were there signs that nursing staff were actively engaged in the case? Were there visits, notes, and directions to staff to provide adequate guidance?

**End of Life Planning / MOLST**

End-of-life planning may occur for deaths due to rapid system failure or as the end-stage of a long illness. Effective January 21, 2011: The MOLST (Medical Orders for Life Sustaining Treatment) form and the MOLST Legal Requirements Checklist should be completed in compliance with the Health Care Decisions Act of 2003. If you are not familiar with the MOLST process please refer to the OPWDD.gov website for more information.

http://www.opwdd.ny.gov/opwdd_resources/information_for_clinicians/MOLST

- What was the content of the MOLST order? DNR? DNI? Artificial hydration/ nutrition? Future hospitalizations? Antibiotics? Other?

- Was there a MOLST form and checklist in place? (6 steps, in brief, see full checklist on the website)

    1. Identify the appropriate 1750b surrogate.

2. Ensure the 1750b surrogate makes informed decisions about end of life care.
3. Confirm the individual's lack of capacity to make health care decisions.
4. Determine the necessary medical criteria.
5. Notifications made.

- Certify notifications made and no objections.

- Were staff aware of the MOLST? Were the orders followed?

- Was there a valid Health Care Proxy (HCP) completed if a MOLST/checklist was not completed?

- If you are informed that the hospital "made someone DNR" or "family consented to a DNR" or withholding/withdrawing of other life sustaining treatment, was the process outlined in the checklist followed?