# *COMMONWEALTH of VIRGINIA*

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Dear Dr._____,

Thank you for agreeing to see an individual served within the network of the Department of Behavioral Health and Developmental Services. As you know, individuals with significant intellectual disabilities often experience other medical co-morbidities and physical limitations that increase the complexity of their care so we are appreciative of your help in providing them the best service possible.

There are a small number of conditions that historically present significant risk to people with intellectual disabilities. To that end we are providing education to their families and providers about these conditions. Consequently, you are likely to get questions from these critical support people when they accompany individuals to see you, as we are encouraging their attention to these issues. These issues include:

- Choking:
- Recurrent aspiration pneumonia, facilitated by Dysphagia and GERD
- Bowel obstruction
- Recurrent urinary tract infections
- Seizures, sometimes very refractory to treatment
- Skin breakdown/decubitus

In addition, individuals with intellectual disabilities are more susceptible than the general population to acute cardiac arrest usually consequent to a myocardial infarction. Some of their added risk for mortality from these conditions derives from their medical vulnerability because they may have a number of medical problems and may have more difficulty as treatment or surgery is provided. Given these realities we are trying to anticipate and prevent the development of, and consequences from, these kinds of problems.

Thus, you can expect to see and hear from families and providers about:

- <u>Choking and aspiration</u>: Diet consistency such as mechanical soft or pureed, feeding protocols, active management of GERD and dental hygiene, review or re-assessment following episodes of choking or aspiration pneumonia, etc. Sedating medications or those with anticholinergic properties may pose an added risk in individuals with chewing/swallowing deficits.

- Bowel obstruction: A heightened sensitivity to constipation with clear diet and medication plans to avoid it. Anticholinergic agents and others that may slow bowel motility may pose a greater than average risk. Review of treatment after episodes leading to ER visits, hospitalizations.
- UTIs: A focus on peroneal hygiene, hydration, urinary retention – all of which may require very active staff attention.
- Skin breakdown: Positioning, observation/monitoring of the skin, early intervention, and treatment fidelity.
- Seizures: Appropriate frequency of follow-up with Neurology/Epileptology, caution regarding medications that may lower the seizure threshold, ongoing attention to drug levels and side effects
- Cardiac risk: Management of diabetes, hyperlipidemia, weight, activity, use of low dose aspirin when appropriate, diet, etc.

A couple of other points may arise in the treatment interactions that may be of interest:

Changing Medication Regimens: Some of the individuals we serve have very complicated bowel, feeding, and medication regimens. Typically, the regimens have been arrived at by lengthy, often "trial and error" attempts to achieve an adequate result. Many are sensitive to change, particularly environmental but also medical. Thus, changing Medications or other treatment regimens should involve a great deal of caution in the first several months following a transition to the community.

Quality of Life: I have found that "quality of life" considerations are often less clear in this population. The risks that go with, for example, eating (for a person with Dysphagia), ambulating independently (when there is a gait/balance deficit), independent toileting (when there may be a hygiene issue), seizure control/risk versus excess sedation or limits on activity, etc. may or may not be offset by the pleasure the activity brings to the person. As is the case when treating some geriatric individuals I would not be surprised if you find yourself engaged in such considerations with families, Guardians, and other caretakers as well as the individuals themselves, if they are able to articulate them.

Again, I want to thank you for your willingness to help with the care of this individual and wish you well in doing so.

Sincerely,

Jack Barber, MD
Interim Commissioner