From Dr. Escudé...

Gastrostomy and Jejunostomy Tube Considerations in People with Intellectual and Developmental Disabilities (IDD)

For Clinicians

G and J tubes are commonly used in people with intellectual and developmental disabilities (IDD) for malnutrition and/or for prevention of aspiration.

For people with severe reflux and continued aspiration with a G-tube, occasionally, a combination of a G and a J tube, either as 2 separate tubes or as one tube with 2 ports, has been successful in reducing aspiration from reflux. When dual tubes are used, the G-tube is used for draining and the J-tube is used for feedings. Using 2 separate tubes rather than the combination tube allows for the replacement of the tubes by a nurse rather than having to have the tube replaced radiographically or with endoscopy.

Here are a few considerations that may differ slightly from neurotypical patients:

- People with IDD may communicate pain through behaviors rather than using words, a painful tube insertion site or intra-abdominal process may cause behavioral changes including verbal or physical aggression especially when the tube is being manipulated or when feedings are being administered.
- Repeated episodes of vomiting may be caused by the bulb of a Foley or G-tube being maneuvered into a position that blocks gastric emptying by peristalsis. Securing with a flange or using a Mic-Key tube may alleviate this issue.
- Some people will repeatedly attempt to remove a tube. Some helpful considerations include using a using a Mic-Key tube, using an abdominal protector, or wearing a leotard to cover the tube area. If a person is repeatedly removing a tube, consideration should be given to the tube being painful to the person.
- It is possible that upon replacement of a tube, the tube may not have entered the stomach or J-jejenum and may cause an abscess.
• Skin irritation around the tube site may cause considerable discomfort and, in turn, aggression in people with IDD.
• Though many with IDD have progressive and long-term disabilities, consideration should be given to returning the person to oral nutrition and removing the tube whenever possible. This is particularly applicable when the tube was placed during an acute phase of an illness and the person has recovered.

Thanks for your careful attention to helping improve the lives of people we support.

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Dr. Escudé has dedicated his career to providing healthcare for people with IDD and other vulnerable populations and teaches on the subject throughout the country.