Caring for the Patient with Autism:

Coordinating Care in a Subspecialty within a Large Hospital Organization

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MGH 1811 MASSACHUSETTS GENERAL HOSPITAL

Objectives

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- Describe autism and co-morbid gastroenterology presentations, as well as other health related conditions, and unique challenges these individuals face within healthcare contexts
- Improved knowledge of communication and calming strategies care providers can use to support patients with ASD/IDD
- Describe systems improvements in outpatient and procedural areas that support the individual with autism, with aim for participant to implement within an institution
- Identify tools and resources that can be utilized across several different hospital departments (outpatient clinic, procedural area of endoscopy, radiology and other diagnostic procedures)
- Knowledge of how to implement tools based on patient need, presentation and departmental context

Neurodiversity

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- “The concept of neurodiversity provides a paradigm shift in how we think about mental functioning. Instead of regarding large portions of the American public as suffering from deficit, disease, or dysfunction in their mental processing, neurodiversity suggests that we instead speak about differences in cognitive functioning…The idea that there is one “normal” or “healthy” type of brain or mind is a culturally constructed fiction, no more valid than the idea that there is one “normal” ethnicity, gender or culture.” ~ Dr. Thomas Armstrong

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Autism Spectrum Disorder (ASD)

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Image credit: Rebecca Burgess "Understanding the Spectrum" https://the-art-of-autism.com/understanding-the-spectrum-a-comic-strip-explanation/

Autism Spectrum Disorder (ASD)

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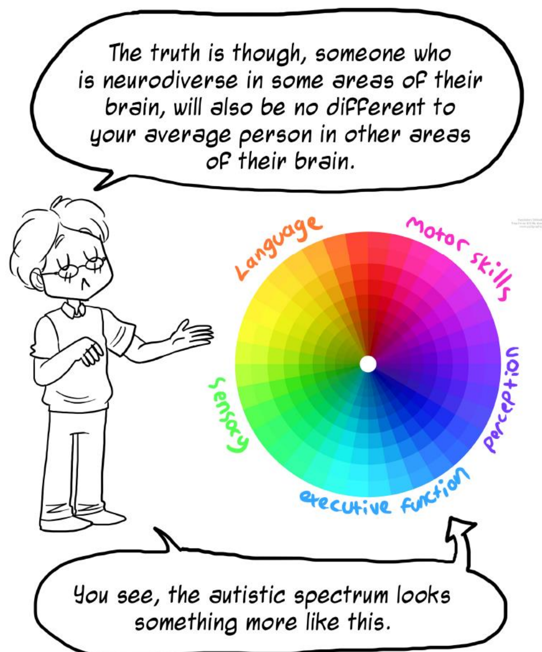

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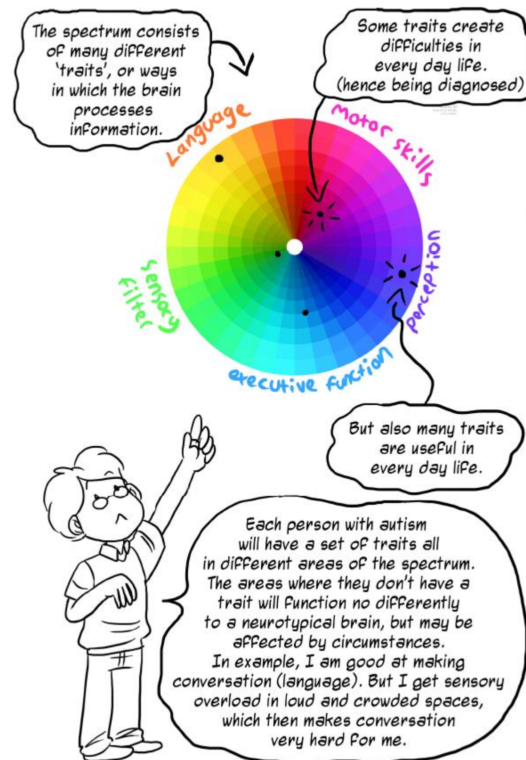

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Autism Spectrum Disorder Diagnostic Criteria

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- Deficits in social communication and social interaction
  - Social-emotional reciprocity
  - Nonverbal communicative behavior
  - Developing, maintaining and understanding relationships
- Restricted, repetitive patterns of behavior, interests or activities
  - Stereotyped or repetitive motor movements, use of objects, or speech
  - Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
  - Highly restricted, fixated interests that are abnormal in intensity or focus
  - Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment
- Center for Disease Control and Prevention reporting prevalence of 1 in 59 among 8 year olds as of 2014

(Diagnostic and Statistical Manual of Mental Disorders, 2013)

A Patient Story: YM

- YM is a 32 year old female with autism spectrum disorder who arrives to the clinic with her mother
- She communicates through gestures, vocalizations and actions, but does not use any spoken language (non-verbal)
- When anxious, will exhibit self-injurious behaviors and aggression
- YM lives in a group home with 3 other young women with ASD and 24 hour staffing assistants. She attends a day program during the weekdays. She sees her mother often and spends weekends with her.

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YM: Medical History

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- Medical History:
  - Epilepsy
  - Generalized anxiety disorder
  - Intellectual functioning disability
  - Gastroesophageal reflux disease
  - Constipation
  - PICA
  - Subclinical hypothyroidism

- Medical settings are stressful for YM due to previous poor experiences

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YM: Symptoms Leading to GI Evaluation

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- Lifelong constipation with intermittent diarrhea
- History of PICA resulting in small bowel obstruction requiring surgery in 2010 and again in 2015
- Parent seeking a second opinion for intermittent abdominal pain, diarrhea despite a bowel regimen that has improved her constipation

- Current prescribed medications for bowel regimen:
  - docusate sodium 100 mg capsule daily
  - psyllium 2 tsp daily
  - simethicone 1 tablet every morning
  - senna 1 tablet daily
  - polyethylene glycol 17 grams every morning and 8.5 grams every evening, each dose mixed in 8 ounces liquid

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Pause...

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What do you think about this scenario?

- What do you think you would want to achieve in this visit (not including curing the patient)?
- Do you think there will be challenges to overcome in this visit?
- What have been your experiences? Any similar situations?

Important Pearls...

- Patients with ASD have anxiety, deficits in communication and behavior that limit their medical care (Kopecky et al., 2013)

- In the Journal of Pediatric Healthcare, providers noted challenges in the healthcare setting which largely include poor cooperation, fearfulness, and communication difficulties of which parents also could confirm and relate to (Bultas et al., 2016)

These points show that there a lot of challenges limiting the patient from the care they need and deserve!

Co-Morbid Conditions

- Epilepsy affects 20-33% of individuals with ASD, compared to 1-2% of general population
- Chronic gastrointestinal disorders are 8x more common in individuals with ASD
- Between 54-70% have 1 or more mental health conditions
  - ADHD, anxiety, depression, schizophrenia, bipolar disorder
- As many as 4 in 5 children with autism have one or more chronic sleep problems
- Feeding and eating issues affect 70% of individuals with autism

(Autism Speaks, 2017)

Mortality and ASD

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- Twice as likely to die prematurely, with the risk as high as 10x the general population for some subgroups
  - Average lifespan of **36 years old** in US (1367 people with ASD between 1999 and 2014)
  - Accidental injury – 160x more likely to drown compared to children without ASD

- Women with ASD are at high risk for in-hospital mortality
  - Almost 2x higher odds compared to men with ASD
  - 3x higher odds than women without ASD

(Akobirshoev, 2019; Autism Speaks, 2017)

Need for Specialists

- 98.9% of parents of children with ASD reported the need for at least one specialist
  - GI, neurology, PT/OT/speech, Dental, mental health and behavioral services
- Children with ASD require a greater number of visit to their primary care provider and sub specialists
- There is a great deal of need for behavioral support as well

(Todorow et al., 2018)

Trauma Prevalence in Individuals with Intellectual and Developmental Disorders

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- Compared with their peers without disabilities, children with intellectual and developmental disability (IDD) are
  - 2x more likely to experience bullying and emotional neglect, physical and sexual abuse
  - 3x more likely to be in families with domestic violence
  - 4x more likely to be victims of a crime
  - Experience traumatizing incidents of physical restraint and seclusion
  - Significantly higher rate of serious injury from traumatic events

- *Increased risk of psychological distress due to medical procedures*

(The National Child Traumatic Stress Network, 2004)

Autism Spectrum Disorder & Trauma

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- 44-77% of children with ASD experience trauma (bullying, peer victimization)
- Experience of trauma may be unique
  - Characteristics of ASD, such as sensation, perception, social awareness and cognition, may alter what events and stimuli are experienced as traumatic
- Communication and cognitive challenges impact coping
  - May show more severe emotional reactions due to lack of social support networks, language delays, and social awareness
  - May have difficulty understanding or managing physical and emotional responses to trauma resulting in pain, behavioral changes or regression
- Hyper-alert state can persist beyond the event to the point of the individual being in a near-constant hyper-alert state
- Experience stigma related being “labeled” with diagnosis

(Haruvi-Lamden, Horesh, & Golan, 2018; Munir, 2016)

Barriers to Accessing Healthcare

Autism-related challenges affecting healthcare access: Communication

- Unable to process information fast enough to participate in real-time discussions about healthcare
- Difficulty communicating with providers or staff
- Literal interpretation of language affects ability to respond to questions
- Need for consistency, slow processing speed, atypical non-verbal communication and challenges with organization

(Nicolaidis et al., 2015; Raymaker et al., 2017)

Barriers to Accessing Healthcare

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Autism-related challenges affecting healthcare access: Sensory Processing

- Lights, smells, sounds in facilities cause discomfort
- Sensitivities make tests screening and exams difficult or impossible
- Sensory sensitivities impact interactions
  - "Lights in the office are very bright…waiting rooms are crowded…I feel disoriented by being led down long hallways to different rooms… I am not able to bring up my concerns because it is all I can manage to figure out what the doctor is saying so I can respond to his questions. He refills my usual meds and I go on my way."
- Challenges with body awareness
  - "Like when they ask if pain is shooting or stabbing or burning, it's like, I don't know, it just feels funny."
  - "It is difficult for me to isolate specific sources of pain and identify duration and intensity. It's sort of like the equivalent to white noise."

(Nicolaidis et al., 2015; Raymaker et al., 2017)

Recommendations to Address Barriers

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- Needs in the medical home
  - Education on ASD for providers and staff
  - Improved care coordination efforts specific to their needs
  - Tailored visits to the patient's needs
  - Additional time with patients to address any gaps in care as well as any caregiver concerns

- "Autism spectrum disorder warrants an integrated approach to their healthcare given they often have more co-morbid health conditions, require more visits to sub specialists and have greater behavioral health needs"

(Todorow et al., 2018)

Systems Improvement: MGH GI ASD Clinic

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- Leadership support
- Hired nurse practitioner with experience
- Provider and staff training
- Considerations for day of week and time of day
- Team: MD, NP, RN, administrative support
- Collaboration and coordination with autism specialty clinic (MGH/MGHfC Lurie Center for Autism)
- Collaboration and coordination with MGH Patient Navigator for Autism and Developmental Disorders

GI Clinic Patient Survey Results

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We surveyed 10 patients with ASD and/or families within our GI clinic...

- Nearly all parents/caregivers found long wait times, crowded spaces/waiting rooms, loud noises, patient not being able to eat, nearby unfamiliar people, bright lights and fast paced visits to be ongoing barriers to care

- Furthermore 6 out of 10 patients were reported by themselves or their parent/caregiver to have anxiety before and during an outpatient GI clinic visit

YM: Symptoms Leading to GI Evaluation

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- Main Symptoms:
  - Abdominal pain
  - Random yelling
  - Intermittent pacing
  - Belching
  - Refusing meals
  - Diarrhea
  - Fecal incontinence- stool leakage

- Previously occurred with severe constipation but improved for years with current bowel regimen until the past 1-2 years

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YM: Current Bowel Pattern

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- Stools are several times a day on this regimen instead of every couple of days leading to agitation and pain
- No hematochezia or melena
- No hard stools or perceived straining
- Infrequent stool leakage or accidents; this is attributed to toilet regimen and pattern being in place as well as improvement in bowel pattern
- Toilets herself but needs assistance for cleaning

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YM: Signs of Abdominal Pain

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- Head banging
- Pacing
- Yelling, clinging to her parent
- Fast eating resulting in food regurgitation and rumination tendencies
- Other common symptoms for this patient include fecal incontinence with consumption of matter
- Prior GERD/reflux symptoms improved with PPI therapy
- Symptom for chest pain would result in throwing her body onto furniture

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YM: Evaluation and Diagnostics

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- Stool culture and studies including for c-difficile were all negative
- Abdominal X-ray and CT scan negative for obstruction
- Stool Transit Study: No remaining markers; moderate stool burden in the sigmoid colon
- Colonoscopy: Negative
- 2011 Upper Endoscopy: Mild gastritis; no h pylori; no celiac disease.
- Lactulose Breath Testing: Negative for Small Intestine Bacterial Overgrowth

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GI ASD Clinic: Preparing for the Visit

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- Obtain all records before visit and scan into chart for easy visit access
- Coordinate with Patient Navigator for ASD/DD
- Develop Patient Accommodations Care Plan in electronic medical record
- Set time for patient scheduling (ie. Thursday, first or second appointment of the session. Allow for ample time: 90 minute consult and 60 minute follow up.)
- Communicate with all involved staff (secretary, medical assistant, phlebotomy, nursing, NP/PA/MD/OT):
  - Patient anticipated needs
  - Accommodations to be implemented during the visit from check in to check out.

GI ASD Clinic: Check-In & Waiting Area

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- Front desk promptly lets medical assistant know when patient checks in to decrease time in waiting room, with ability to coordinate walking directly to exam room if needed
- Clinic scheduled at time when waiting room is less noisy and less crowded
- Large space
- Sensory tools (encouraged to bring their own): IPADs, DVD machine, noise canceling headphones, weighted lap pads
- Available tools: mini-simulations doll, glove balloons
- Meet basic needs
  - Access to snacks or drinks with considerations for special diets and allergies (gluten, dairy and nut-free options)
  - Bathroom nearby and clearly marked

GI ASD Clinic: In the Exam Room

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- Large room- no clutter!
- Access to switch/dimmer lights
- Visual cues during vital signs-online pdf access for providers to utilize as needed
- Provider reviews pre-visit care plan
- Addresses **patient** and family
- Get to know your patient!
- Step-wise/slow/patient driven physical exam
- Allow the patient to leave when uncomfortable
- Comfort or distracting items: Glove balloons, magazines, patient can bring own soothing items to visit
- Allow pacing
- Allow patient to express concerns

Patient Navigator for ASD/DD

- Improve Quality of Care
  - Resource
  - Advocacy
  - Coordination and collaboration among teams
  - Education and training

- Improve Systems of Care
  - Continuity of care
  - Process improvement

- “Every patient with ASD is NOT really unique” for developing hospital systems

- Funded philanthropically by The Ruderman Family Foundation

Patient Navigator Process

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Referral	Patient Outreach	Preparation	Day-of Support	Future Support
•Provider offices •Pre-Procedure Evaluation Phone Calls •Procedural areas •Patient or Family member	•Gather information •Create Patient Accommodations Care Plan	•Collaboration with staff caring for patient •Update medical record •Provide patient with tools •Arrange familiarization visit as indicated •Communicate final plan with patient and staff	•Contact with patient and family •Support staff •Manage unanticipated challenges •Offer direct care and interventions as needed	•Ongoing relationship with patient and family •Revise and update care plan as needs evolve •Consistent presence for staff

Systems Improvement

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Patient Accommodations Care Plan

- Need for documentation of non-medical accommodations needs in an accessible location in the electronic medical record

Category	Patient Accommodations Care Plan
Safety Concerns	**Current history of the following with potential to occur during MGH visit**: ☑ Aggression: Verbal only; may swat both hands up/down but not directed at others **If occurs, best approach is to**: ☑ Give him/her some space then, ☑ Talk to him/her **Comment**:
Medical Setting Needs	**Tolerates:** ☑ Vital signs (blood pressure, temporal temperature, O2 monitor on finger) ☑ ID band on wrist or ankle ☑ Changing into and wearing hospital clothing ☑ Riding on stretcher ☑ Needles (blood draw, IV) ☑ Items touching nose/face (ie. Mask over nose and mouth) ☑ Sticky textures on skin (tape/bandaids/EKG leads) ☑ Physical exam **Comment:**

Needs Accommodations Due To Poor/Limited Tolerance:
Waiting room ☑ Quiet/private space to wait **Comment:** - Has difficulty tolerating waiting of any kind
Hospital Room ☑ Private room with a door/Quiet environment ☑ Dimmed lights **Comment:** Tolerates dim or natural light
Hospital Clothing ☑ Needs assistance to dress/undress into hospital clothing
ID Band ☑ No accommodation needed
Physical Exam/Vital Signs **Comment:** Blood pressure on **RIGHT** arm ☐ No accommodation needed
Hospital Procedures **Comment**: IV and blood draws on **LEFT** arm (less sensation in left arm d/t impairment from stroke)
Transport/Stretcher ☑ No accommodation needed

Systems Improvement

Patient Accommodations Care Plan

- Pain and Other Safety Related Concerns
  - Expression and experience of pain
  - Actions or behaviors that impact safety (e.g. self-injury, aggression, PICA, bolting)
- Medical Setting Needs and Accommodations
  - Tolerance for busy areas, hospital gown, ID band, vitals, physical exam
- Communication Needs and Strategies
  - How a person expresses him/herself, receptive language abilities, communication of yes/no and basic needs, strategies
- Comfort Needs and Strategies
  - Stressors and signs of upset/anxiety, sensory sensitivities and soothers, calming strategies, distraction techniques and special interest
- ADL Needs and Strategies
  - Toileting, medication administration, sleep, diet/eating preferences
- Other Considerations
  - Visual, hearing or physical mobility impairments

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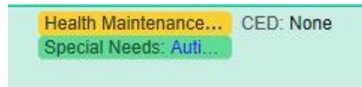
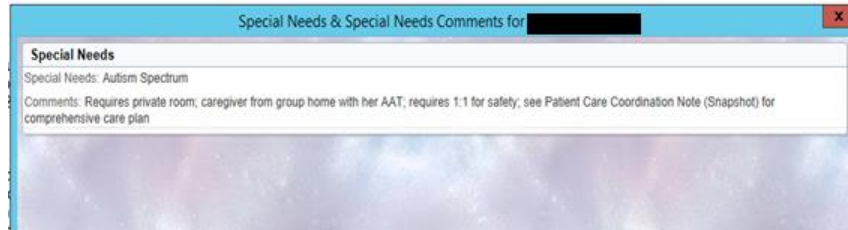
Special Needs Flag - Autism Spectrum Disorder

- Flag in electronic medical record for patients who self-identify as having a disability and need accommodations





Systems Improvement

MGH Champion for ASD/DD Network

- The MGH Champion for Autism and Developmental Disorders is an individual who is interested in improving the care of patients with ASD/DD, highly motivated, and a change agent and informal leader within his or her department

- ~90 Champions from a variety of departments and role groups throughout the hospital
  - Nursing, physicians, police and security officers, chaplaincy, social work, therapies, and administrative roles
  - Representation from the emergency department, procedural areas, perioperative services, inpatient units, and outpatient offices
  - Gastroenterology was one of the first collaborations!

Systems Improvement

Procedural Areas

- Identify a Champion/Champion team - What is a Champion?
- Review current process and determine alternatives
  - Identify each step of the process for the patient, from parking and entering the building to each demand of the procedure
  - Consider what options are available for each step – be flexible with environment and 'rules' (i.e. allowing pt to pace instead of remaining in room)
- Communicate the plan to all involved

Systems Improvement

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Procedural Areas

Endoscopy Accommodations

- Prep alternatives for those who cannot tolerate traditional prep
- Reduced waiting time
- Bypass waiting room when safety issue
- Private bay with door
- Consistent nurse pre & post procedure
- Wear own clothing and changed once asleep if needed
- ID band held by parent/caregiver until patient is asleep
- Can walk/wheelchair to procedure room instead of pushed on stretcher
- Vitals and weight may be deferred until asleep if patient unable to tolerate
- Coban as alternative to tape

CT Accommodations

- Accommodations for prep discussed based on each CT test's needs
- Flexible appointment times
- Expedite waiting in waiting room
- Scheduling on high-performance CT scanner to maximize efficiency of test
- Remain in own clothing if wearing plain t-shirt and elastic waist pants
- Room with scanner has choice of colors
- Strawberry or chocolate flavor for barium
- Private/quiet spaces for IV placement

Systems Improvement

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Procedural Areas

Barium Swallow Accommodations

- Flexible appointment time
- Skip waiting room and expedite to testing room upon arrival
- Wear own clothing from home
- Flavored Drinking barium contrast option (strawberry vs. chocolate)
- X-Ray machine options (20 inch vs. 40 inch from patient)
- Body positioning is flexible during test (standing, seated or lying down)
- Trusted caregiver allowed to reposition patient with guidance from radiologist instead of unfamiliar person
- Lighting on or off

Ultrasound Accommodations

- Flexible appointment time
- Allowing patient to touch all materials/tools prior to being applied
- Trusted caregiver allowed in procedure room
- Skip waiting room and expedite to testing room upon arrival
- Wear own clothing from home
- Body positioning is flexible within some limits
- Limited room traffic
- Tactile items available for patient to use during procedure

YM: Procedure Needs - Lactulose Breath Test

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2 unsuccessful previous attempts

Demands of the test:

Day of Test

- Brush teeth in AM but don't swallow toothpaste or water
- Take only meds that must be taken at specific AM time (i.e. seizure meds), hold other medications until after the test

Steps of Lactulose Test

- 2 hour Test
- Drink a cup of water mixed with syrup (lactulose). This may cause diarrhea in some patients.
- For the first 20 minutes: breathe into the bag every 5 minutes
- For the next 40 minutes: breathe into the bag every 10 minutes
- For the last hour: breathe into the bag 1x every 30 minutes
- Total: 11 breaths

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YM: Procedure Needs

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Care Plan developed with input from group home staff and mother.
Some key components include:

- **Communication:** YM is nonverbal, and understands well when she is calm (ability deteriorates when distressed). When she is happy she is sweet and loving. Strategies:
  - Speak to her in normal tone of voice using direct language, allow her time to respond to requests.
  - Demonstrate what you need her to do; model on a trusted caregiver
- **Triggers that lead to Anxiety/Upset**
  - Hospital/medical environments
  - Not being able to eat/hunger
- **Warning Signs & Signs of Crisis** (occur only when she is most distressed)
  - Hair pulling
  - SIB: hits self with open palm against head
  - Aggressive behavior: head butting, biting (self and others)
- **Strategies for Calming**
  - Private room
  - Familiar caregiver
  - Eating/food
  - Sensory fidgets (spinners)
  - Walking
  - Looking at food magazines/feeling pages
  - Special interests: Disney, Music (Adele)
- **Sensory Needs**
  - Sensitive to: loud noises that are unexpected, being touched
  - Seeks: Seeks movement, tactile stimulation

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YM: Preparing YM for the Breath Test

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- Bag mailed to group home for home practice prior to day of procedure
- First-Then Picture Schedule
- Incorporation of special interest

Then, Kyle will give you a bag to blow in to. It is the same one you used to practice at home.

Then, you blow into the bag like you are blowing a bubble, just like Ariel.

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YM: Day-Of Support for Breath Test

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- Pre-procedure check in with staff
- Greeting patient and group home members at building entrance
- Observation and interpretation of YM's current presentation
- Trial of tool use, and revision of plan when didn't have an impact
- Supported "meeting YM where she was at"
  - Meeting sensory needs: Walked laps for 90 minutes
  - Meeting comfort needs: Listening to music, involvement of familiar group home staff, involvement of special interests
  - Meeting cognitive/communication needs: Counting down use of visual timer, praise, use of positive reinforcer, minimizing spoken language, "first...then" language

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Systems Improvement

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Procedural Areas

- Create a Patient Accommodations Care Plan
- Review accommodations agreed upon by procedural area with patient and family and outlines plan for the test
- Prepare the patient: materials, visuals, dry-run if possible and appropriate, incentives if appropriate
- Provide 1:1 support for most complex cases (i.e. failed previous attempt) - there is often ‘in the moment’ things that change, but knowing about patient via care plan helps to guide those decisions so that it’s seamless

Wrap Up

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Key Points..

- Every patient is unique - it is important to understand the individuals' needs
- Tailor the patient's needs to your care plan and work flow
- This is not a "one size fits all" approach!
- Slow and steady is often better.
- Always look for areas of improvement.
- Safety is number 1 priority.
    - Identify a problem/situation
    - Anticipate needs
    - Communicate with patient and family
    - Allow enough time and be flexible
    - Be Creative and Patient!

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Thank You

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Confidentiality has been maintained throughout entire presentation and identifiable characteristics as well as patient name has been removed.

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