IntellectAbility
REPLACING RISK WITH HEALTH AND WELLNESS

Actions Speak Louder Than Words:

Behavioral Manifestations of Common Medical Conditions in People with IDD

Presented by:

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- Over 20 years of experience caring for people with mental illness and intellectual and developmental disabilities
- Medical Director of Hudspeth Regional Center in Whitfield, MS – Retired 2018
- Founder of DETECT
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- Host of the *IDD Health Matters Podcast*

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Melissa

- 26-year-old female
- Ambulatory
- Independent with eating, dressing, grooming
- Feeds herself a regular diet
- Urinary incontinence
- BM every 1-2 days on the toilet
- Non-verbal with limited sign language and gesturing
- Oriented to person, place and time
- Pleasant and mostly cooperative

Melissa

- Diagnoses:
  - Moderate IDD
  - Anxiety

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Melissa

- New onset of fecal incontinence

Differential

- Fecal incontinence with smearing
  - 1-2 times a month
- Behavior analyst monitored
  - Attention seeking behavior

Melissa

- Frequency of fecal incontinence increased
- Verbal and physical aggression noted
  - Making loud noises at staff
  - Threatening
  - Shaking fist
  - Invading other’s space
  - Sexually acting out

Consultation

Melissa

- Psychiatric evaluation
  - Seroquel started
- Anger and aggressiveness improved
- Fecal incontinence continued

Other Information

Melissa

- Behavior noted to be worse preceding weekends she went home with her grandmother and for a couple of days after return
- Grandmother related she noted no similar behavior at home and there were no untoward events

Melissa

- Behaviors continued with addition of curling herself up in a recliner before grandmother picked her up to go home

Melissa

- Psychiatric follow up
  - Seroquel dose increased
- Further discussion with GM revealed that when Melissa's father visited at her grandmother's house, anger and physical aggression toward her grandmother occurred after his visits.
- Episodes were short-lived and GM did not think much about them

Melissa

- Further investigation revealed …
- Sexual abuse by her father
- When father was no longer allowed to visit, all symptoms resolved
- Seroquel was discontinued

Melissa – Take Home Points

- Behavior is communication
- A change in behavior often indicates an underlying issue
- Knowing the baseline of a person is important
- Use caution when treating behaviors with anti-psychotics
- When behaviors do not resolve as expected or worsen, get more information

Behaviors Associated with Sexual Abuse

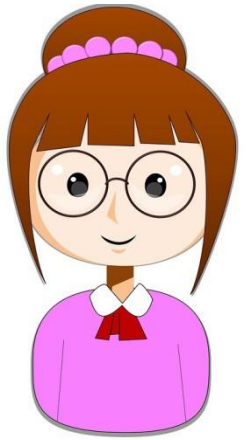
- New onset urinary or fecal incontinence
- Withdrawal
- Excessive masturbation
- Refusal to allow bathing or aggression during bathing
- Self restraint (wrapping self inside shirt, wrapping blanket or throw tightly around themselves, knees to chest and hugging)
- Sexual aggression toward others
- Agitation
- Verbal or physical aggression when approached by caregiver or others - especially if the person shares characteristics with abuser (male, female, tall, short hair, Caucasian, African American)
- Suicidal behavior/attempts
- Night terrors

Sexual Abuse Statistics

- A recent review of statistics by NPR and the US Department of Justice shows that people with IDD are sexually assaulted at a rate seven times higher than those of people without a disability.

Shari

- 45-year-old woman with mild ID
- Lives in a staffed apartment with 2 other women for the past 5 years
- Independently employed in a large department store where she has worked for 3 years as a stocking clerk



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Shari

- Recent onset of epigastric pain, which is particularly intense in the middle of the night
- Consumes her meals in less than 5 minutes and will often raid the refrigerator in the middle of the night. She will strike out if anyone tries to interrupt this behavior
- Referred to a psychiatrist for her aggressive behavior. He placed her on Seroquel in the past 6 weeks
- Her support staff reports that her behavior is increasing, and she is also vomiting intermittently, usually after a meal

Shari

- Referred to a gastroenterologist. She discovered that Shari has Barrett's esophagus and chronic esophagitis
- Started on Proton Pump Inhibitor, which eased her symptoms within 2 weeks
- Her sleep patterns improved

Mary

- 25-year-old female began showing resistance to going to the cafeteria
- Made a gagging sound when food presented to her
- Episodic crying mostly at night

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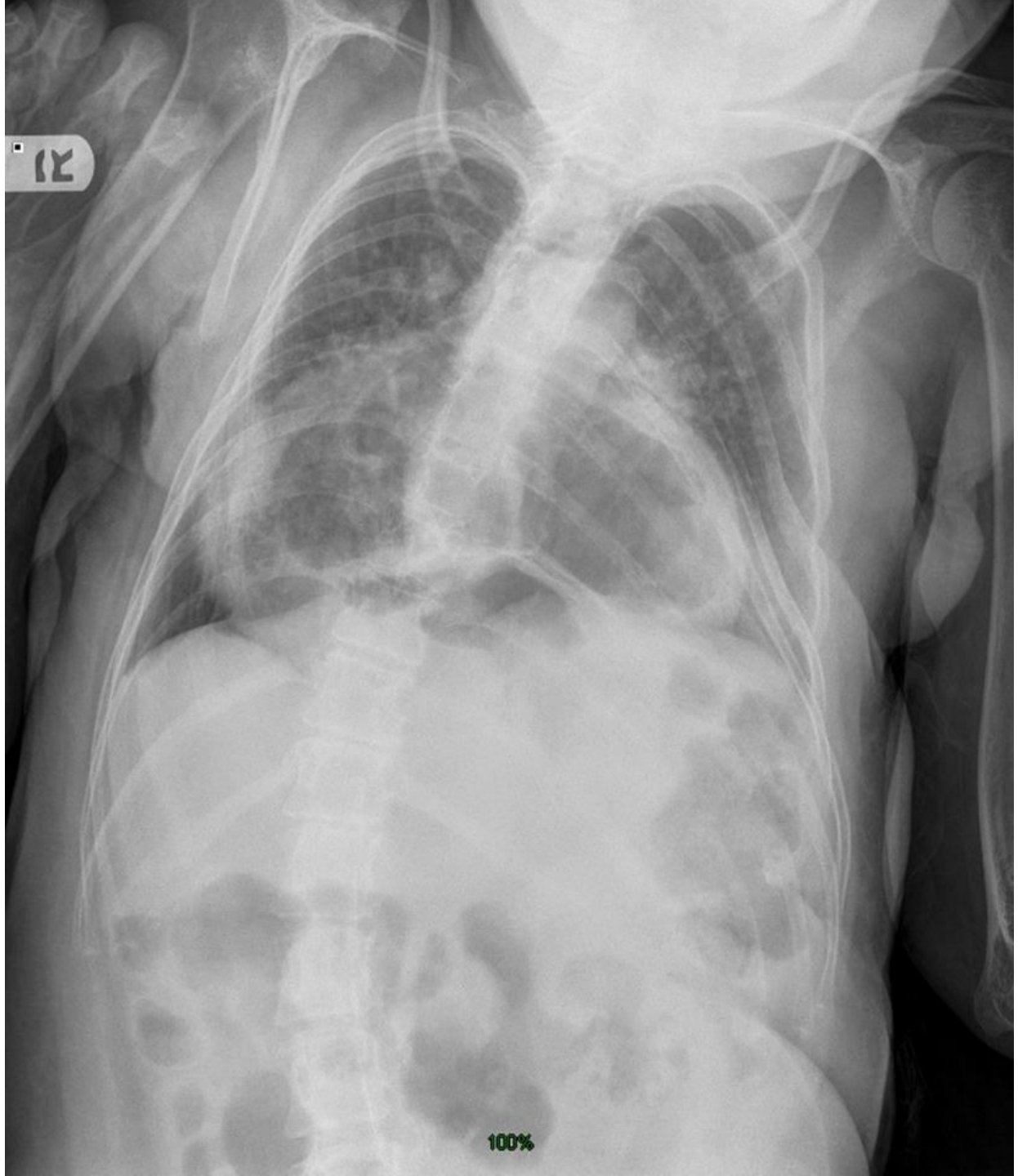
Mary - Exam

- No acute findings

Mary



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Behaviors Associated with GI Distress/Reflux

- Hand mouthing
- Pica
- Food refusal
- Coughing when lying down
- Physical or verbal aggression particularly around mealtimes

J.C.

- 53-year-old male
- Ambulatory
- Independent with eating, dressing, grooming and toileting
- Verbal
- Obsessed with horses
- Loves magazines of any kind
- Talks of flying to an Eastern state to see his sister
- Oriented to person, place and time
- No aggressive tendencies

J.C.

- Diagnoses
  - Moderate IDD
  - Chronic allergic rhinitis
  - Chronic sinusitis
  - Psychotic disorder
  - Anxiety disorder
  - GERD

J.C.

- New onset of physical aggression with staff
- Stealing magazines from everywhere he went
- Attacked staff if they tried to stop him
- Put his head down in magazines but didn’t turn the pages

Differential

Audience Question…

What do you think JC might be telling us?

A. He is tired

B. He is hurting

C. He does not like the staff

D. He likes the smell of magazines

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J.C.

- In a period of increased purulent nasal discharge
- Physician called and antibiotics and steroid dose pack were started

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J.C.

- Behavior
  - Aggression continued but magazine stealing stopped
  - More obsessed with horses than ever
  - Aggression increased with noted property damage, hitting walls and head banging

Consultation

J.C.

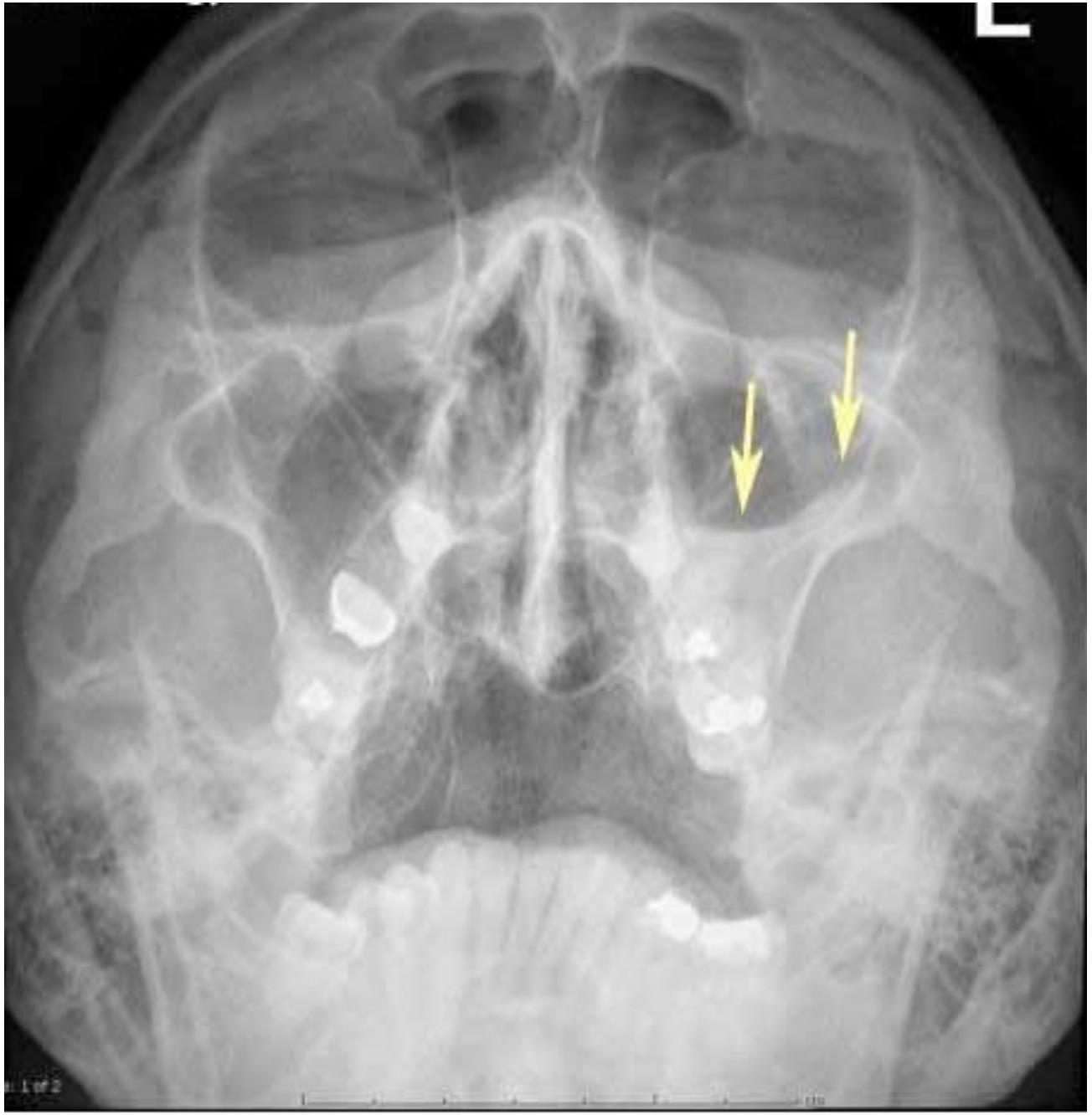
- Psychiatrist
  - Haldol started
  - Behavior changes
  - Shaking
  - Drooling
  - Lethargy
  - Confusion

Next Step

J.C.

- Local ER evaluation
- Sent to tertiary care center
  - Meningitis
  - Sepsis
  - Pneumonia
  - Bilateral sinusitis with complete opacity of maxillary sinuses
- Not able to breathe or eat well and had silent aspiration

J.C.



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J.C. – Take Home Points

- New behaviors should be taken as a form of communication
- Just because someone has always had a particular condition does not mean that it could not lead to other complications
- Use caution when treating behaviors with medications
- Some side effects of medications can also be signs of a serious medical illness

Behaviors Associated with Head Pain

- Head banging
- Head butting
- Hitting or slapping self
- Inserting objects into ears or nose
- Crying
- Withdrawal from areas with light or noise
- Sitting with head in lap
- “Refusals” to listen or respond (loss or reduction in hearing)
- Hands over ears or face
- Tilting head to one side

Behaviors Associated with Medication Side Effects

- Blinking
- Medication refusal
- Refusal to eat
- Urinary or fecal incontinence
- Constipation
- Urinary retention
- Aggression
- Fatigue
- Weight gain or loss
- Agitation
- Scratching self
- Falls, change in cognitive status
- Tics, dystonic symptoms
- Muscle twitching

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Dennis

- 32-year-old male with severe ID
- Could make guttural sounds but most of the time could make needs known
- “Coffee” was one word that was always understood and would drink multiple cups all day if allowed
- Always wanted to be around staff and peers and was friendly and outgoing
- Dependent on staff for all ADLs
- Could feed self but with significant spillage and great enjoyment of mealtimes
- Excessive oral secretions
- On mechanical soft diet due to poor dentition

Audience Question…

What condition is Dennis at most risk for?

A. Abuse

B. Dermatitis

C. Dehydration

D. Aspiration

E. Falls

Dennis

- Diagnoses
  - Severe IDD
  - Severe DJD
  - HTN
  - Psychosis

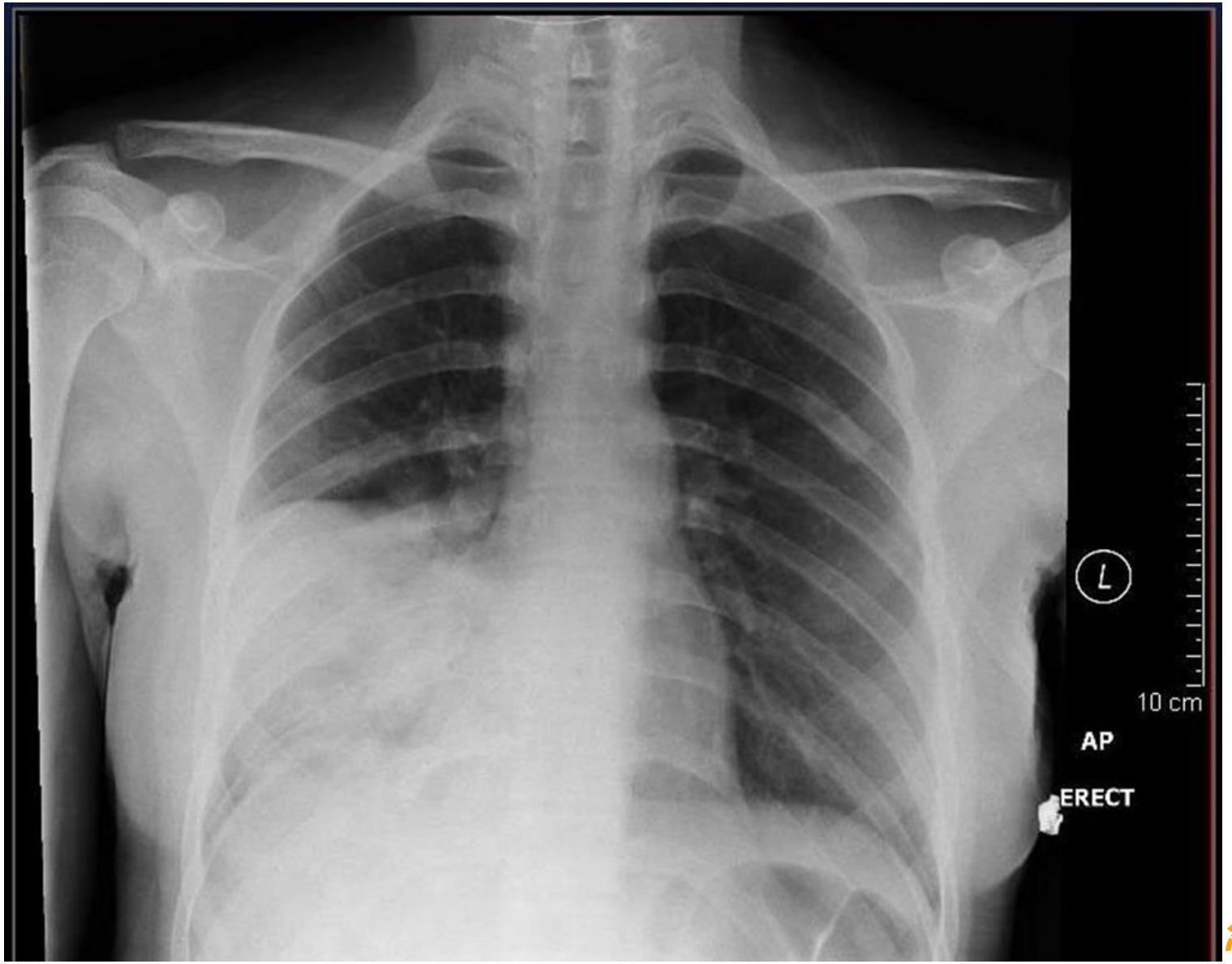
Dennis

- On a Sunday evening…
  - Sudden onset of fatigue and wanted only to go to bed immediately after eating normal dinner
  - Staff had him stay up awhile
  - Refused his HS snack and would not drink coffee
  - Would not interact with peers
  - Irritable
  - Vital signs within his baseline

Dennis

- Sent to ER per nurse's orders
- Diagnosed with pneumonia and admitted to ICU
- Ventilator dependent within 48 hours and never able to be weaned
- Died in 4 weeks due to pneumonia and sepsis

Dennis



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Dennis – Take Home Points

- Always pay attention when someone says “He’s not acting right” or “She’s not eating”
- Aspiration can occur silently – without obvious coughing, choking or vomiting episodes

Behaviors associated with Pneumonia

- Fatigue
- Withdrawal
- Refusal to eat
- Falls
- Increased irritability
- Change in cognitive status
- Refusal to lie down to sleep

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Sue

- 28 y/o female with new onset of repeated banging of her head
- Agitation worse around mealtime
- Not wanting to eat

Thoughts?

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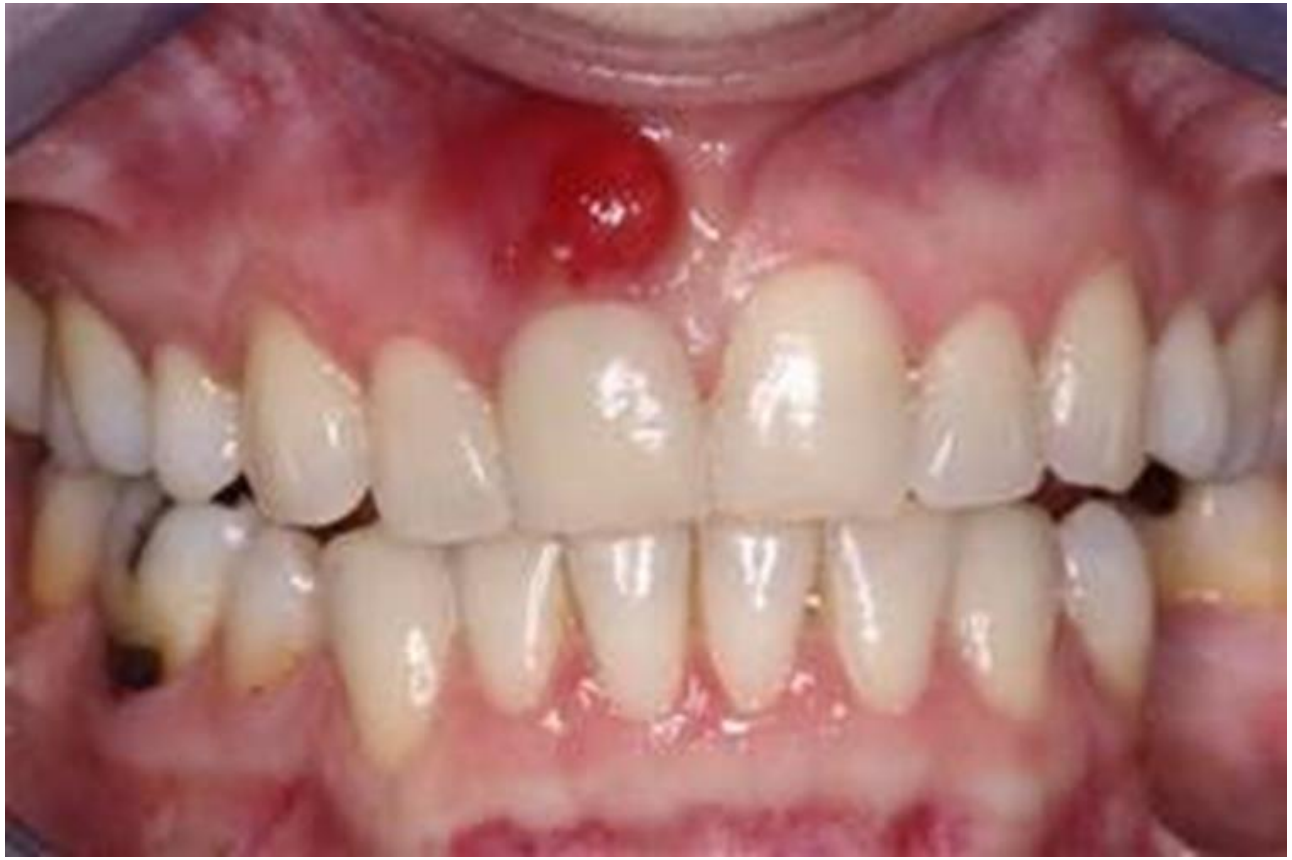
Sue



Patricia

- 49-year-old female
  - Ambulatory with a normal gait
  - Requires assistance with dressing
  - Feeds herself, but “picky” eater
  - Continent, normal B and B habits
  - Non-verbal
  - Aggressive at times
  - SIB-bites right arm frequently

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Patricia

- Medical
  - Profound IDD
- Current Problem
  - Swelling of the right side of her mouth

Consultation

Patricia

- Dental exam
- Dental abscess
- Overall - chronically poor dentition
- Decision made to have a full mouth extraction

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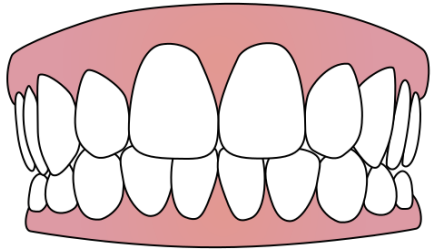
Patricia

- After extraction done
  - NO MORE SIB
  - NO MORE AGGRESSION
  - EATING WELL
  - SMILING AND GENERALLY HAPPY

Audience Question…

Have you ever supported a person that had a better quality of life AFTER a full mouth extraction? (weight gain, eating better, less agitation, less pain)

A. Yes
B. No



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Behaviors Associated with Dental Issues

- Hitting self
- Hands in mouth
- Refusal to eat
- Spitting out food
- Physical or verbal aggression particularly around mealtimes

Chris

- 28 y/o profound IDD with spastic quadriplegia
- Slow progression of lethargy, decreased level of alertness
- Not eating
- Becoming agitated and aggressive at times
- Vomiting

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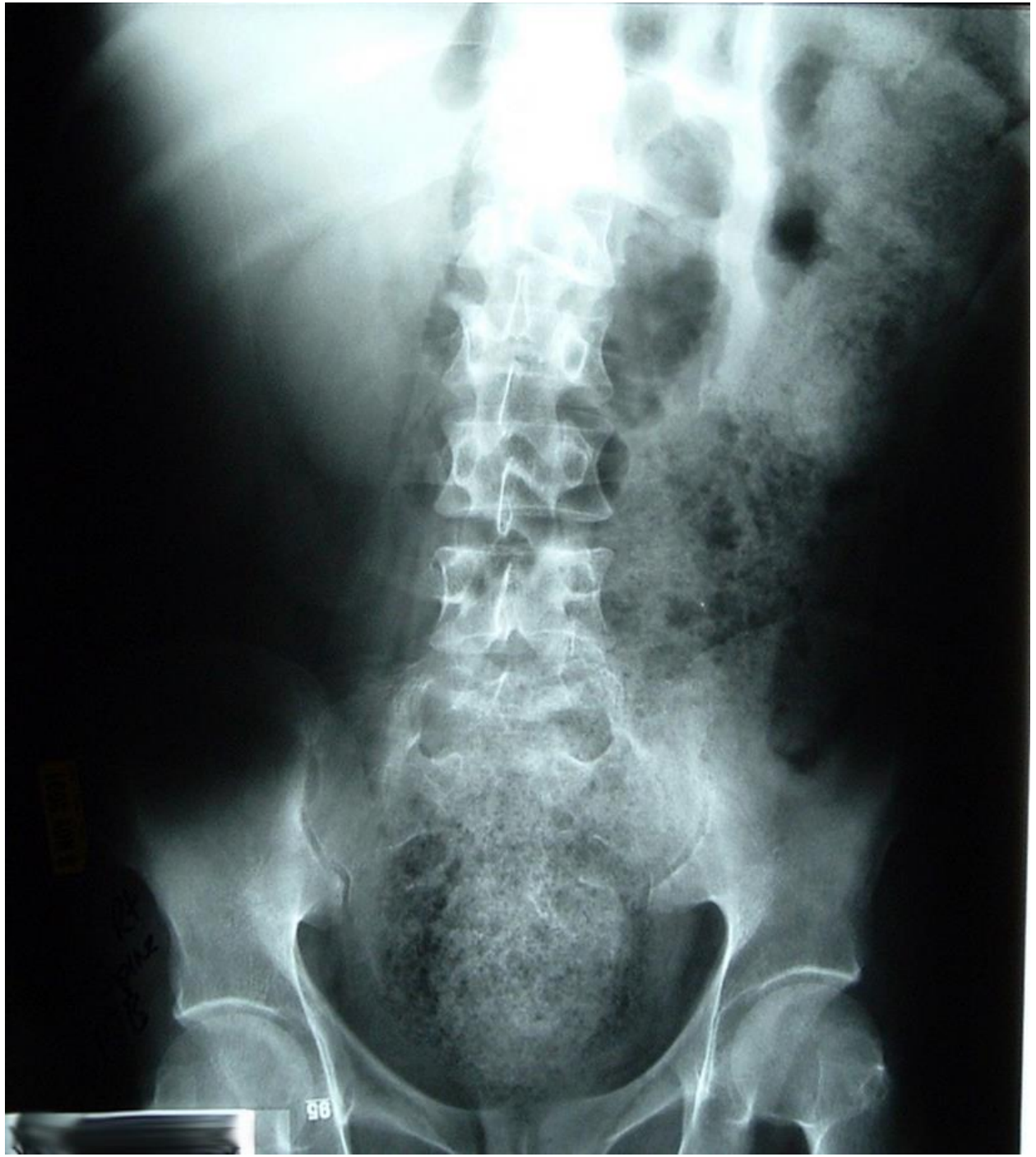
Chris



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Behaviors Associated with Constipation

- Guarding abdomen
- Rocking
- Not able to sit still (up and down)
- Hitting self in abdomen
- Fetal position when lying
- Knees drawn up to chest when sitting
- Physical or verbal aggression without definite antecedent
- Refusal to eat

William

- 19-year-old male with Profound IDD, loves attention and interaction with others
- Dramatically falling to the ground
- Spells of not listening
- Episodes of talking very loudly for a several seconds
- Falling asleep very suddenly

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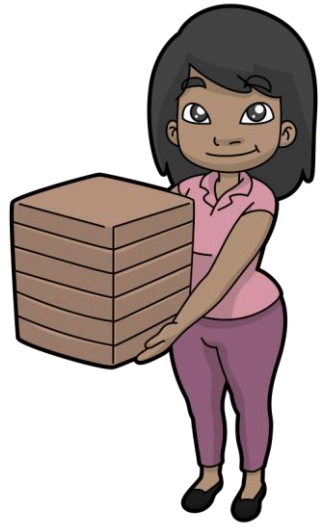
William

- Thought to be exhibiting attention seeking behavior
- Another staff saw it and felt a medical evaluation was indicated
- Diagnosed with a seizure disorder

Sally

- 16-year-old female
- High-Moderate ID
- Ambulatory
- Independent with self-help skills
- Pleasant and interactive most of the time
- Speaks in 3-4 word sentences
- Supported employment 3 days a week



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Sally

- Tonic/Clonic seizure disorder (on medication)
- Usually has 3-4 seizures a year

Sally

- Began showing aggression toward housemates
- No obvious antecedents
- Staff did occasionally notice “staring spells” sometimes and a couple of times they progressed to a full-blown seizure

Sally

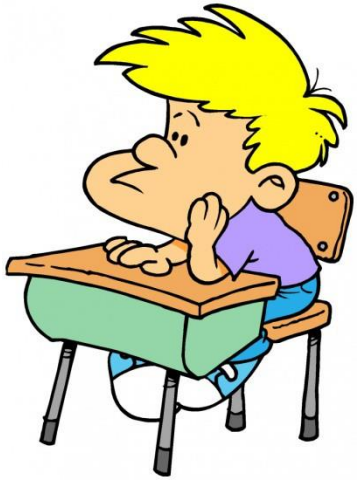
- Referred to an epileptologist
- Diagnosed with focal seizures sometimes becoming focal to bilateral seizures
- Medication added resulting in seizure control in 3 months!

Sally – Take Home Points

- Focal seizures can be difficult to diagnosis
- Harder to diagnose if the person has limited ability to communicate “aura” symptoms
- Important to notice, document and communicate subtle symptoms to help have an accurate diagnosis
- Some behavioral drugs can lessen seizure control
- Todd’s paralysis is a temporary loss of function after a seizure
  - One-sided
  - Facial droop
  - Limping
  - One-sided extremity weakness

Behaviors associated with Seizures

- Disrobing
- Increased agitation
- Failure to “pay attention” in children or “daydreaming”
- Sexually acting out
- Physical or verbal aggression with no trigger
- Repetitive or ritualistic type behaviors that are short lived
- Rapid eye blinking
- Tantrums
- Falls
- Sudden “sleep”
- Random talking
- Hard to “reach”



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Sheila

- 28 y/o female
- Becoming fidgety and could not seem to sit still even during her favorite TV show
- Putting her hands in her pants
- Become upset when assisted to the bathroom and would bite her arm

Audience Question…

Which of these is the least likely diagnosis?

A. Abuse

B. Urinary Tract infection

C. Constipation

D. Dental Abscess

E. Yeast infection

Sheila

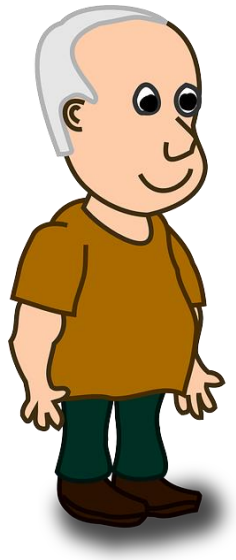
- Urinalysis
  - TNTC WBC
  - Culture positive for E.coli

Behaviors Associated with Urinary Tract Infections

- New onset urinary incontinence
- Agitation
- Not able to sit still (up and down)
- Repetitive trips to toilet
- Screaming when approaching toilet or with incontinence
- Grabbing genitals or rubbing with objects
- Hands in pants
- Physical or verbal aggression with no trigger
- Abdominal guarding
- Rocking
- Change in cognitive status
- Fatigue

Terry

- 69 y/o male usually pleasant, calm, cooperative, not verbal but understands many gestures, continent of bowel and bladder, feeds himself
- Has episodes of pacing the floor
- Nervous appearing
- Anxious
- Starts scratching at his neck and chest
- Starts yelling out with loud vocalizations



Audience Question…

What psychiatric diagnosis is most likely?

A. Depression

B. Schizophrenia

C. Anxiety Disorder

D. Obsessive Compulsive Disorder

Terry

- Appeared to have trouble catching his breath
- Appeared pale
- Seemed weak

Terry

- Taken to the ER
- Diagnosed with a Myocardial Infarction

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Behaviors Associated with Chest Pain

- Scratching, hitting or rubbing chest
- Crying
- Yelling out
- Agitation
- Anxiety
- Shortness of breath
- Weakness

These behaviors might point to what?

- Head banging
- Not eating
- Lethargy
- Curling up in a corner
- Sticking a pencil in ear
- Biting arm
- Shoving a sock in mouth

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These behaviors might point to what?

- Screaming every time a bald man walks into the room
- Becoming agitated when being taken to the bathroom
- Waking up at night crying
- Disrobing
- Frequent falling episodes
- Head tilting to one side

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These behaviors might point to what?

- Rectal digging
- Not paying attention
- Increased aggression
- Resisting going to the cafeteria
- Refusing medications
- Coughing with drinking fluids
- Panic attacks

John

- 28-year-old male
- Non-verbal
- Ambulatory
- Requires help with all ADLs
- Eats independently

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John

- Profound IDD
- Otherwise, healthy

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John

- Was noted by the staff to have a limp one morning
- No report of injury or fall
- First noted when the staff got him up out of bed

Differential

John

- Foot – No redness swelling or tenderness, no pain with ROM
- Knee -normal
- Hip – normal

Consultation

- What else?

John’s Shoe

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John – Take Home Points

- Think Simple First!

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Thank you!

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