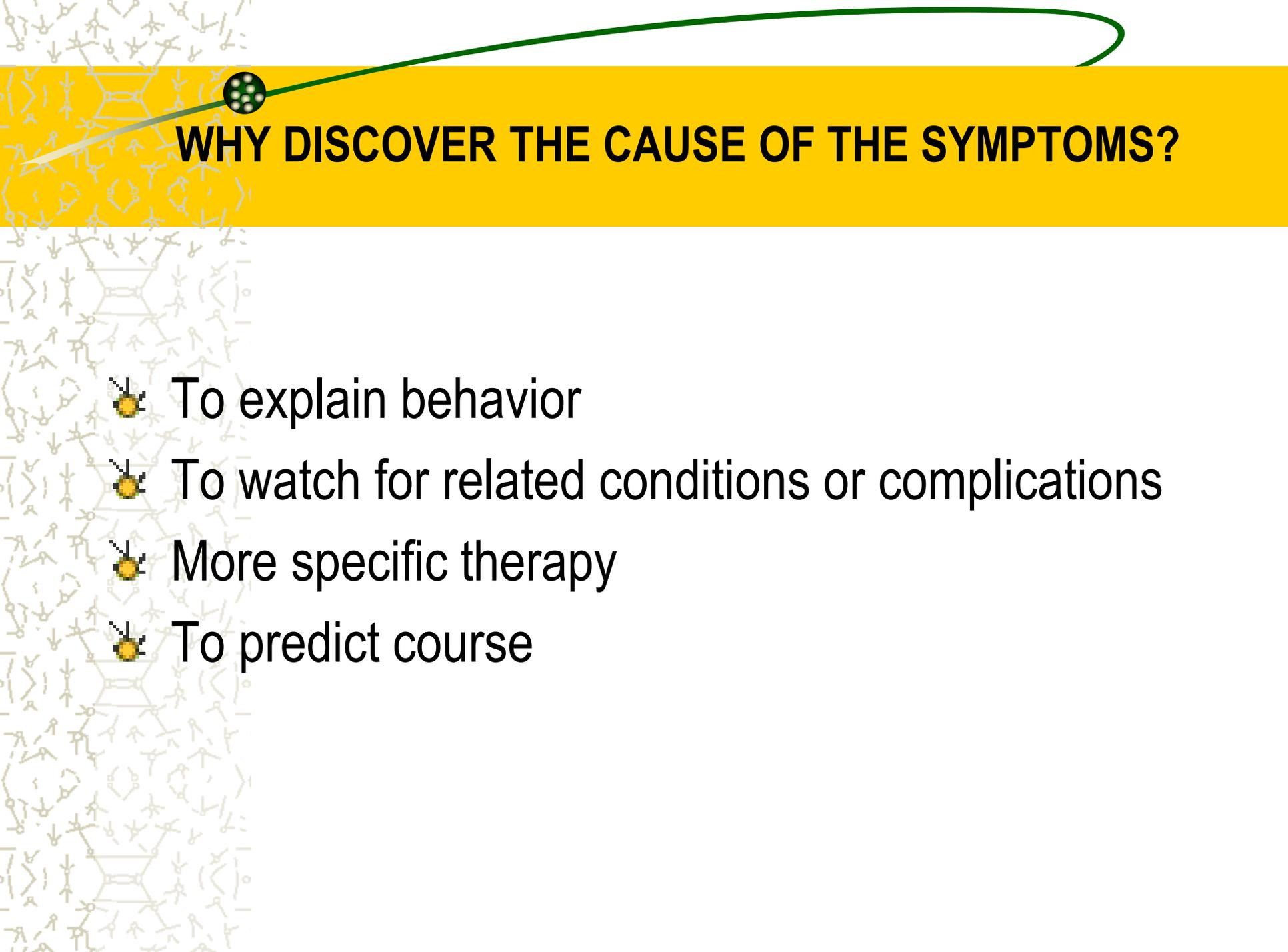


Do You See What I See?

Toni Benton, MD

Carla Fedor, RN, CDDN

Continuum of Care Project



WHY DISCOVER THE CAUSE OF THE SYMPTOMS?

- ✖ To explain behavior
- ✖ To watch for related conditions or complications
- ✖ More specific therapy
- ✖ To predict course

NARROWING IT DOWN



Careful history and physical



Search for more information from informants and past record



Consider unwanted drug effects, drug interactions always



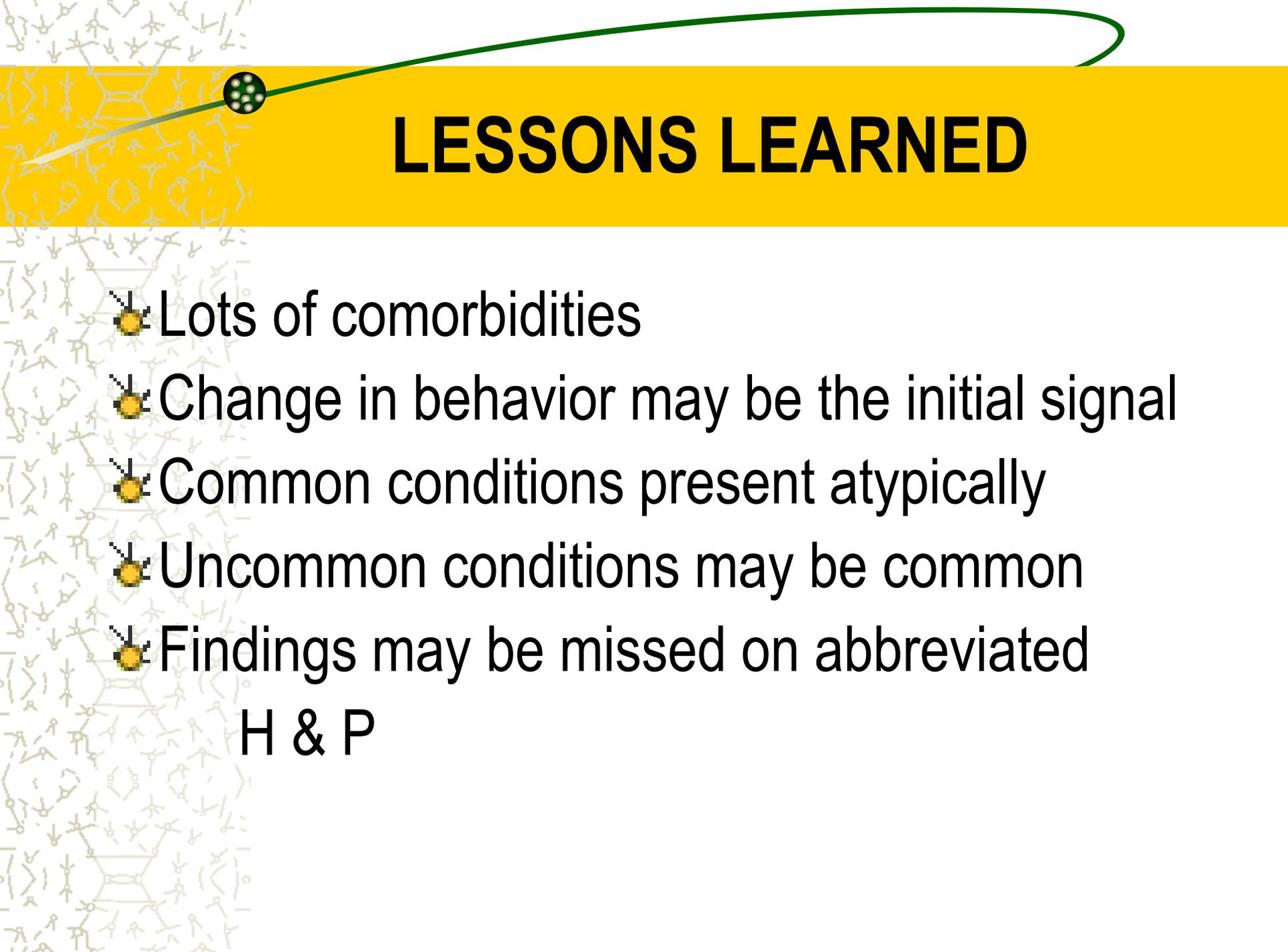
Stepwise evaluations are the best approach



Don't overreact or underreact

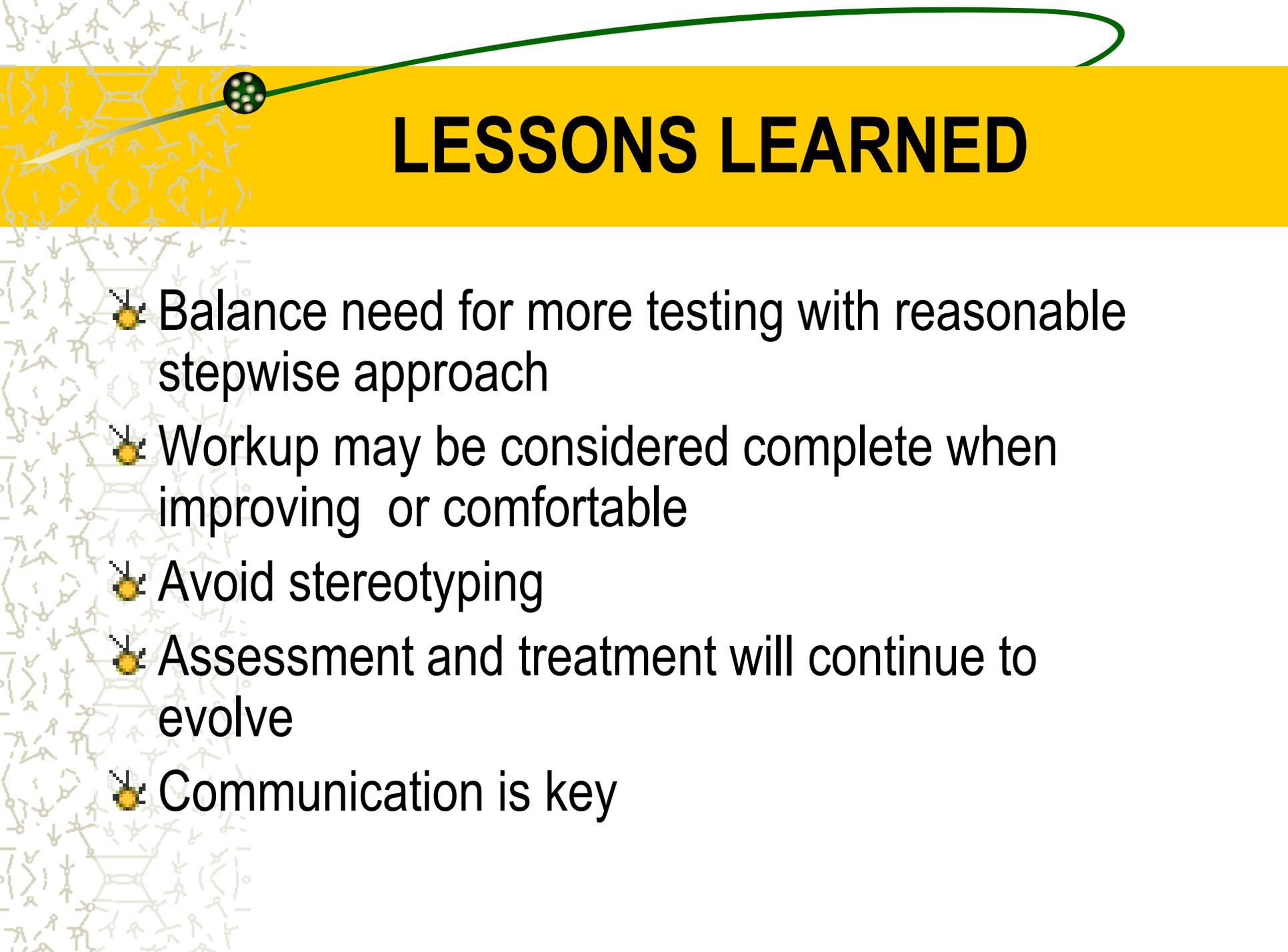


Use PCP first



LESSONS LEARNED

- ✚ Lots of comorbidities
- ✚ Change in behavior may be the initial signal
- ✚ Common conditions present atypically
- ✚ Uncommon conditions may be common
- ✚ Findings may be missed on abbreviated
H & P



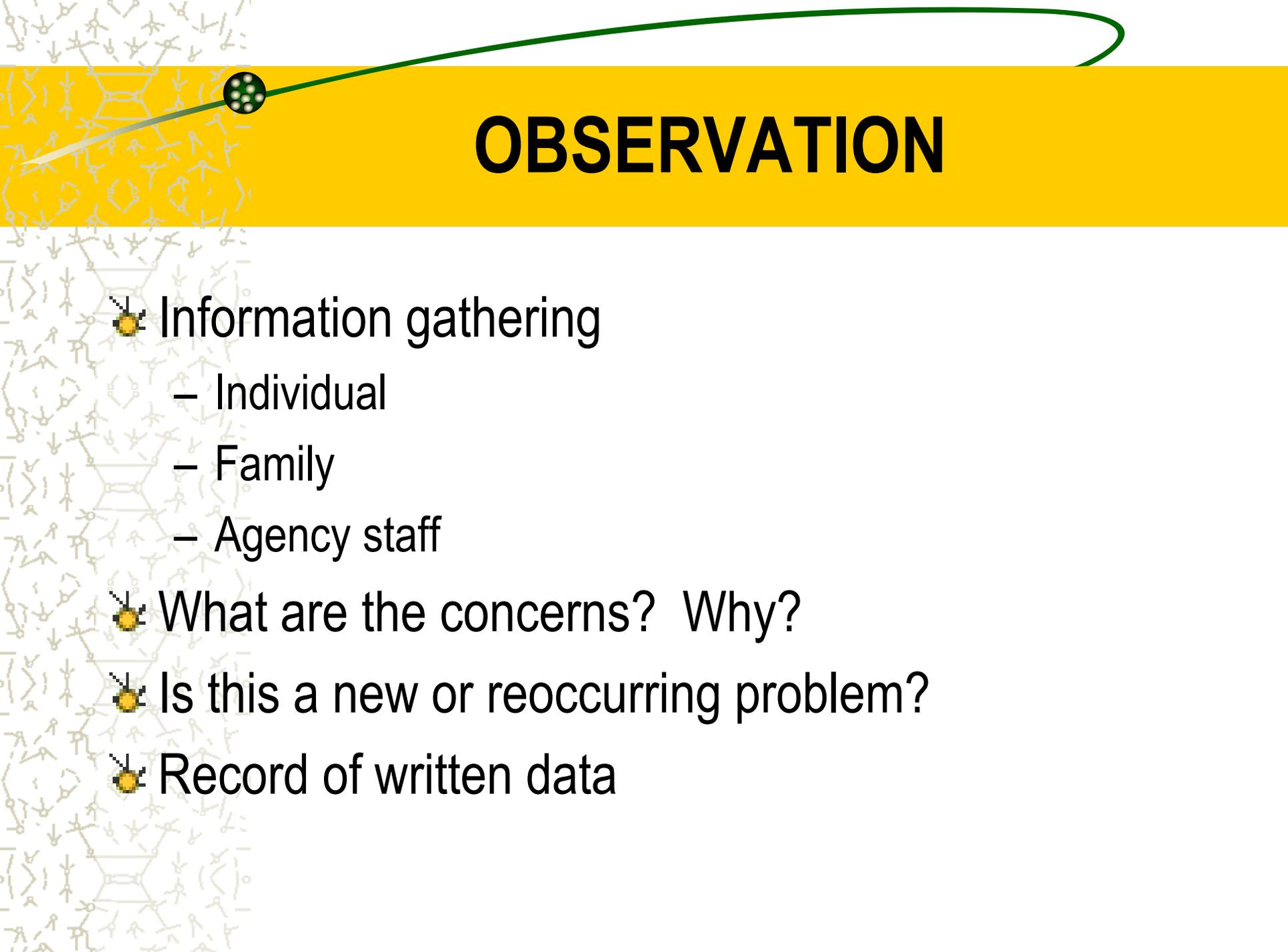
LESSONS LEARNED

- ✦ Balance need for more testing with reasonable stepwise approach
- ✦ Workup may be considered complete when improving or comfortable
- ✦ Avoid stereotyping
- ✦ Assessment and treatment will continue to evolve
- ✦ Communication is key



COMMUNICATION

- ✦ All team members **must** be included
- ✦ Provide complete information
- ✦ Provide information in writing



OBSERVATION

- ✚ Information gathering

- Individual

- Family

- Agency staff

- ✚ What are the concerns? Why?

- ✚ Is this a new or reoccurring problem?

- ✚ Record of written data

WHAT IS BASELINE ?

- ✚ What does the person look like at their normal level of function?
- ✚ How often did the behavior happen prior to noticing a “change”?
- ✚ If a change is noted, it must be compared to the person’s *OWN lifelong patterns*.



WHY IS BASELINE IMPORTANT ?

- ✦ Difference noted from past physical exams
- ✦ Promotes each person as an individual
- ✦ Evaluate the individual's coping strategies
- ✦ Focus on strengths and abilities in planning treatment
- ✦ Directs treatment protocol

CASE SCENARIO 1

- JS is a 24 year old man who has Sturge Weber Syndrome. He has a severe developmental disability, a port wine stain, glaucoma and seizure disorder. He is on a variety on anticonvulsant medications, eye drops, vitamins and bowel aids. Recently, he has been experiencing severe emotional outbursts with damage to property, injury to staff and severe self abuse. He sometimes complains of headaches. Seizures are relatively poorly controlled but this is not new. Recent anticonvulsant levels have been in the therapeutic range. What could be going on here?

CASE SCENARIO 2



WJ is a 39 year old male with a diagnosis of Cerebral Palsy, GERD and seizure disorder. He has profound Mental Retardation. His staff reports that WJ is a very happy person, is very mobile and likes to eat. He has always had some regurgitation but now he regurgitates his food daily, especially in the morning. His weight has remained stable. He has not had a witnessed seizure in several years. What could be going on here?

CASE SCENARIO 3

JB is a 38 year old male with Down syndrome who suffers from GERD and Hypothyroidism. At a visit to his PCP on January 20, he was head banging and his appetite had increased dramatically. Initially, he was treated with Zantac and then Prilosec for his GERD, and Ibuprofen for presumed pain of indeterminate origin. On February 2, he initially improved, according to staff. Ibuprofen and Prilosec were increased. But on March 2, things had deteriorated. JB was wheezing and found to have pneumonia, was hospitalized, and with treatment he improved. Pneumonia reoccurred twice more, accompanied by head banging and lethargy. On May 10, a video swallow study showed that he was an aspiration risk.

A modified diet (thickened liquids only) has decreased the frequency of pneumonias and behaviors. His visits to the psychiatrist for SIB have slowed to none in the past year.

CASE SCENARIO 4

IA is a 71 year old nonverbal male with severe mental retardation, degenerative arthritis, scoliosis and kyphosis. On April 4, he presented to his PCP with cough and fever. He was noted to be leaning to the left in his gait, which was a change from his baseline. His pneumonia was treated and a feeding gastrostomy tube was placed. Subsequently, a head CT scan revealed a frontal infarct (stroke). No source for the stroke was found on further testing. His ability to walk was more limited than it had been before. He began to lose weight, despite adequate nutrition and his left sided weakness worsened. He no longer smiled.

On October 20, in consultation with a psychiatrist, a diagnosis of depression was made and treatment started. He has since improved noticeably.