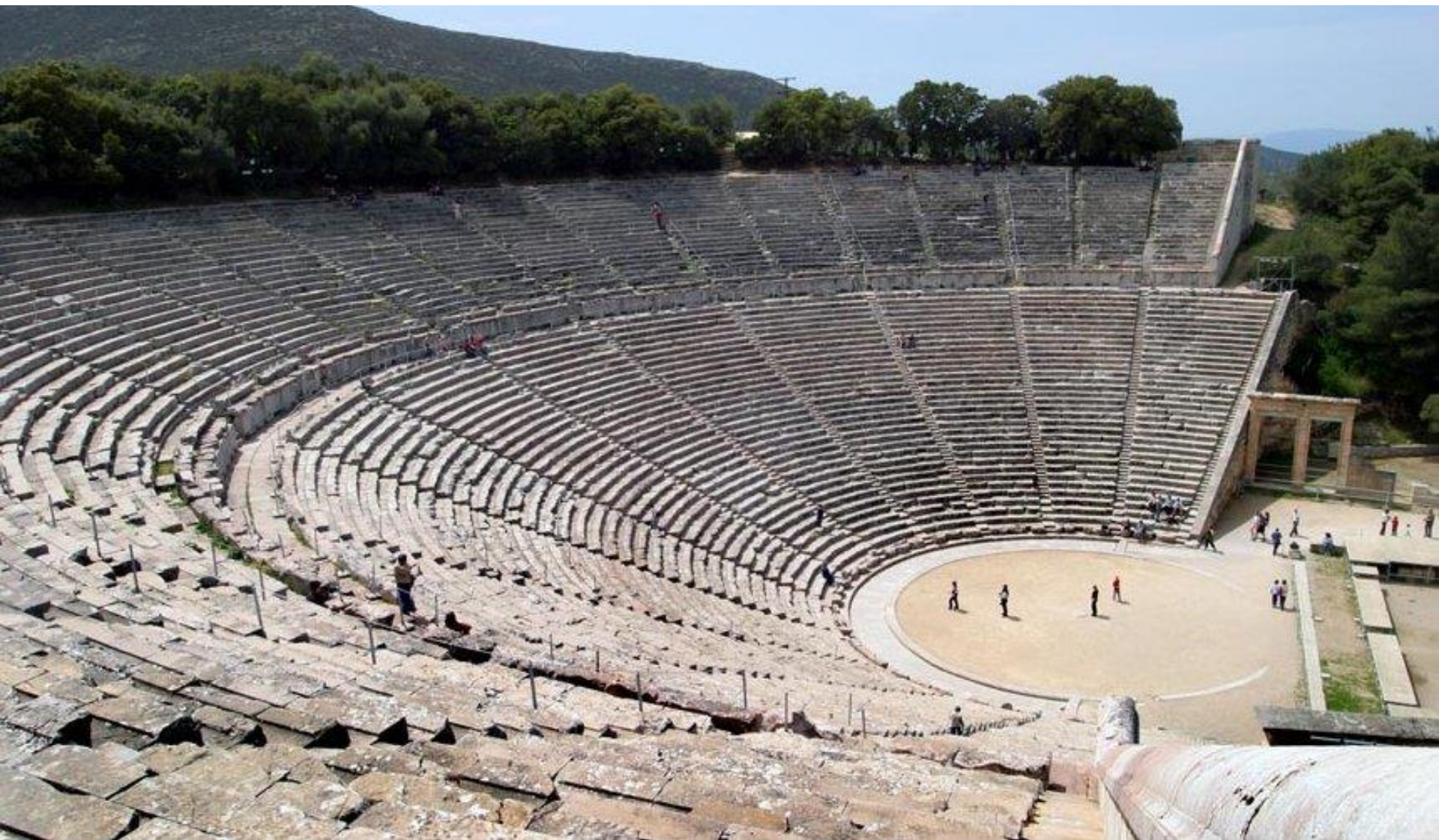


“Huntington’s Disguise”

Huntington’s Disguise







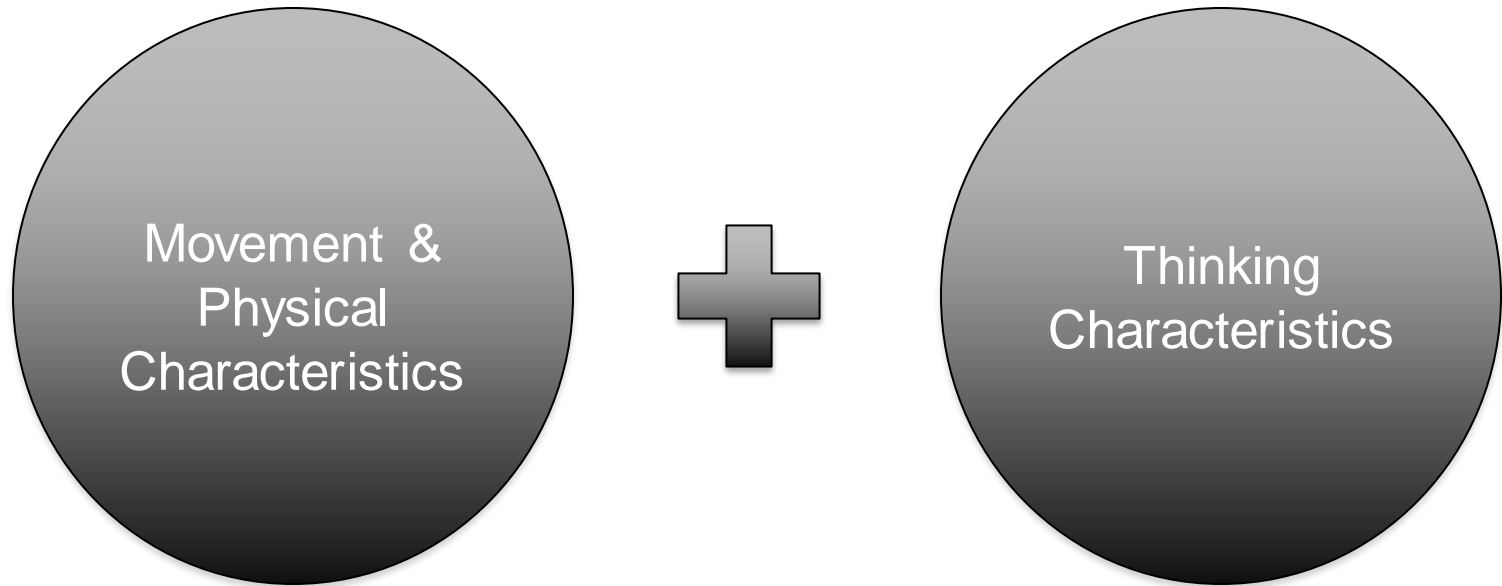


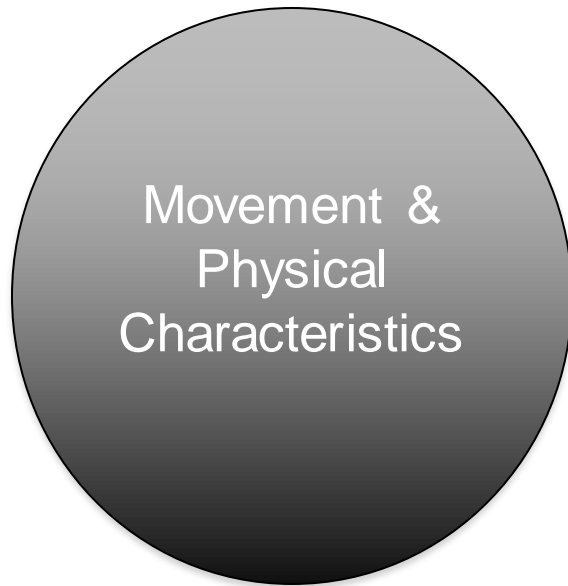
Huntington' s Disguise happens when...

- ...HD' s cognitive characteristics...
- ...and some movement characteristics...
- ...combine to make people appear different than usual and...
- ...makes us believe things that are not true about what they may be thinking or feeling.

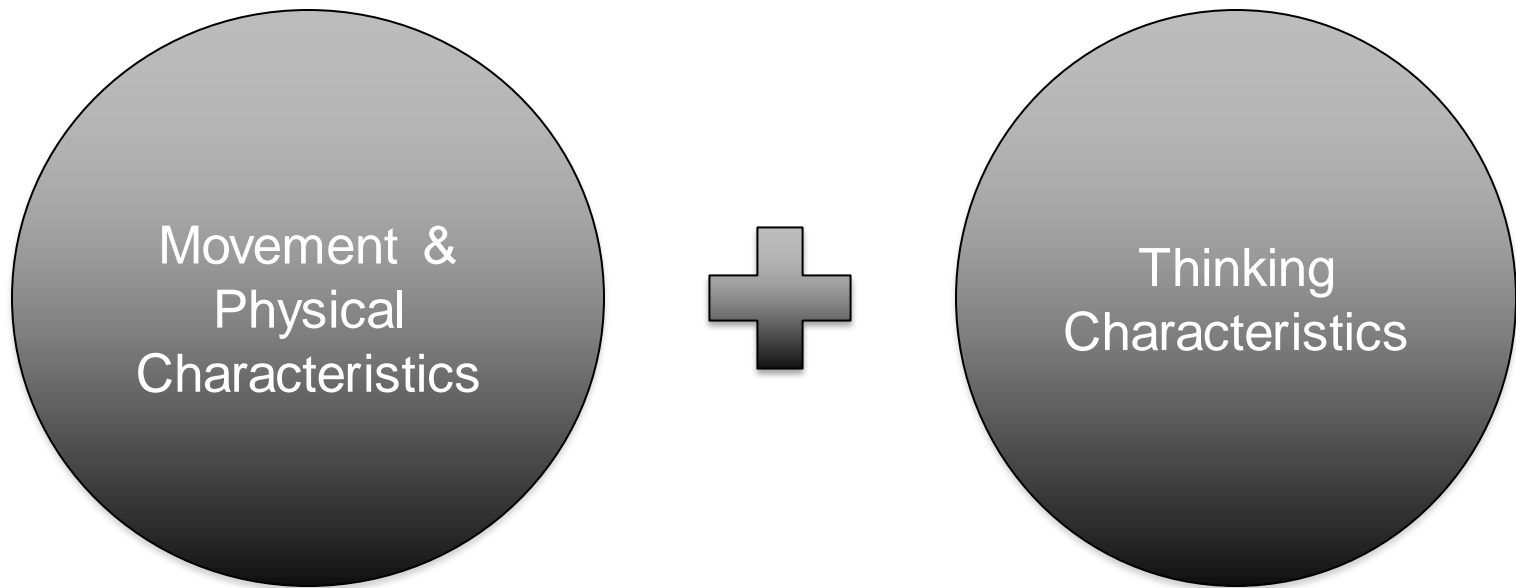
Hopefully...

- If we reveal Huntington's Disguise...
- ...then we can see through it...
- ...and prevent false these beliefs.

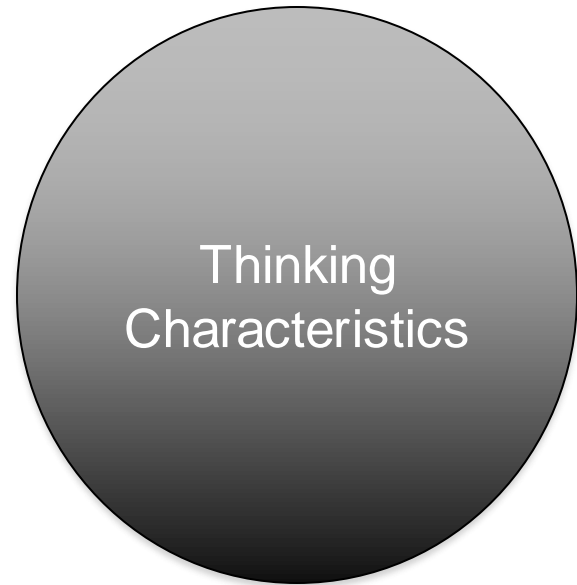




- Weakness in the face.
- Motor impersistence around the eyes...
- ...and smiling.
- Change in posture from dystonia.
- Shoulders in a bit.
- Slouching.
- Flopping into or onto...
- The right amount of force.



- Slower thinking.
- Delays in responding.
- Setting one's ticker back.



Delays can be more ...

- ...on the phone!



- Slower thinking.
- Delays in responding.
- Setting one's ticker back.
- Difficulty waiting.



Can' t wait!

- If you have Huntington' s Disease, you often ask, “What' s taking so long?”
- Together, fill in these blanks:
- “When someone with Huntington' s Disease wants something, they want it _____!!!”
- “It seems that people with HD just can' t _____!!!”
- Isn' t this behavior predictable?

Can't Wait!

I WANT IT:

LATER ○

NOW ○



Can't wait? How we can help?



Slower thinking? How we can help?

- Simply wait.
- For some of us, it's so difficult to do.
- Because he thinks slower, ***wait***.
- And...he can't wait!
- So ***hurry up*** and do for him...as best as you can.
- So...are you telling me...
- For us carers, it feels like...

“Hurry up and wait! Aaaarrrggghhh!!!”



And if you're the person with HD...

It feels like...

“Hurry up!!! What’s taking so long!?! Aarrrgghhh!”



Most seriously, though...



...over the years...

...this is ***a profound act of love.***

...very difficult work.

Some reminder badges...for your junk drawer...



- Slower thinking.
- Delays in responding.
- Setting one's ticker back.
- Difficulty waiting.



We may believe...falsely...

- “He doesn’ t understand what I’ m saying.”
- “He’ s not paying attention to me.”
- “He’ s not answering me. (Immediately).”
- “He’ s only concerned with himself.”

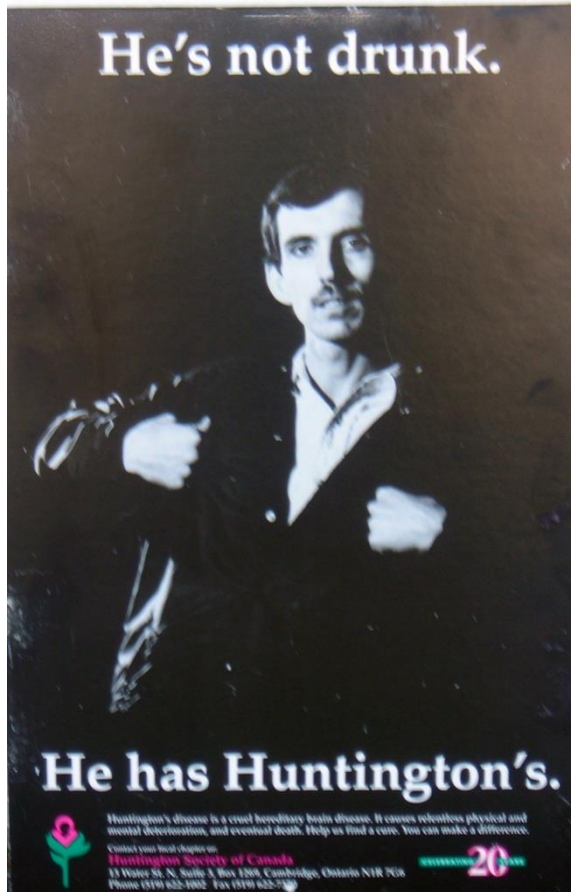
How The Disguise Fools Us...

- “Want to go shopping with me today?”
- (No immediate response...1...2...)
- “Well, do you want to? It’s beautiful outside today!”
- (...3...4...5)
- “No? OK!” (Exits)
- But no response does not mean “No!”
- Perhaps (...7...8) “Yes!”
- Happens one time: “He doesn’t want to.”
- Happens two times: “He’s not interested.”
- Several times: “He never wants to do anything!”

A common delusion

- He has difficulty with...
 - balance,
 - his speech is a bit slurred,
 - he doesn't answer questions quickly,
 - he's got a "short fuse" ...
- "He's drunk!"

A common delusion



More false beliefs, more “Huntington’s Delusions”

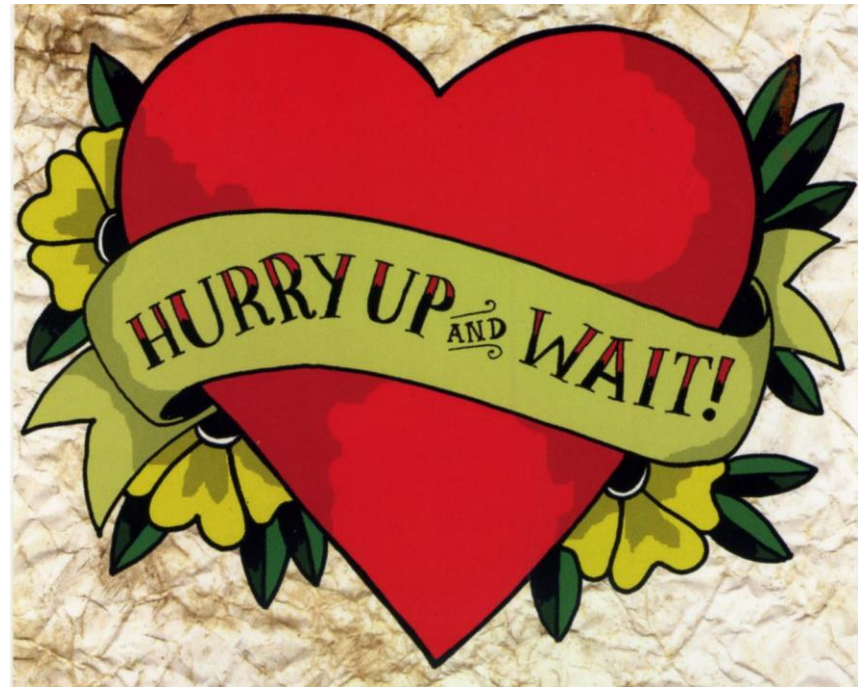
- “He’s not interested.”
- “He’s bored.”
- “He’s lazy.”
- “He doesn’t like me.”
- “He’s impatient.”
- “He doesn’t understand that I just can’t....”
- “He doesn’t understand that there are others...”
- “He doesn’t remember.”
- “He used to be such a happy guy.”

What can we do?

- See through “Huntington’ s Disguise!”
- Use all the accommodations.
 - Slow down.
 - Remember the ticker.
 - One thing at a time.
 - Hurry up and wait!
- Admit mistakes quickly!
- Recognize how one might feel and let them confirm it.
- Wait.
- It’s one more horrible thing...

We're all carers.

- It's serious.
- It's difficult.
- It's hard work.
- ***It's an act of love.***

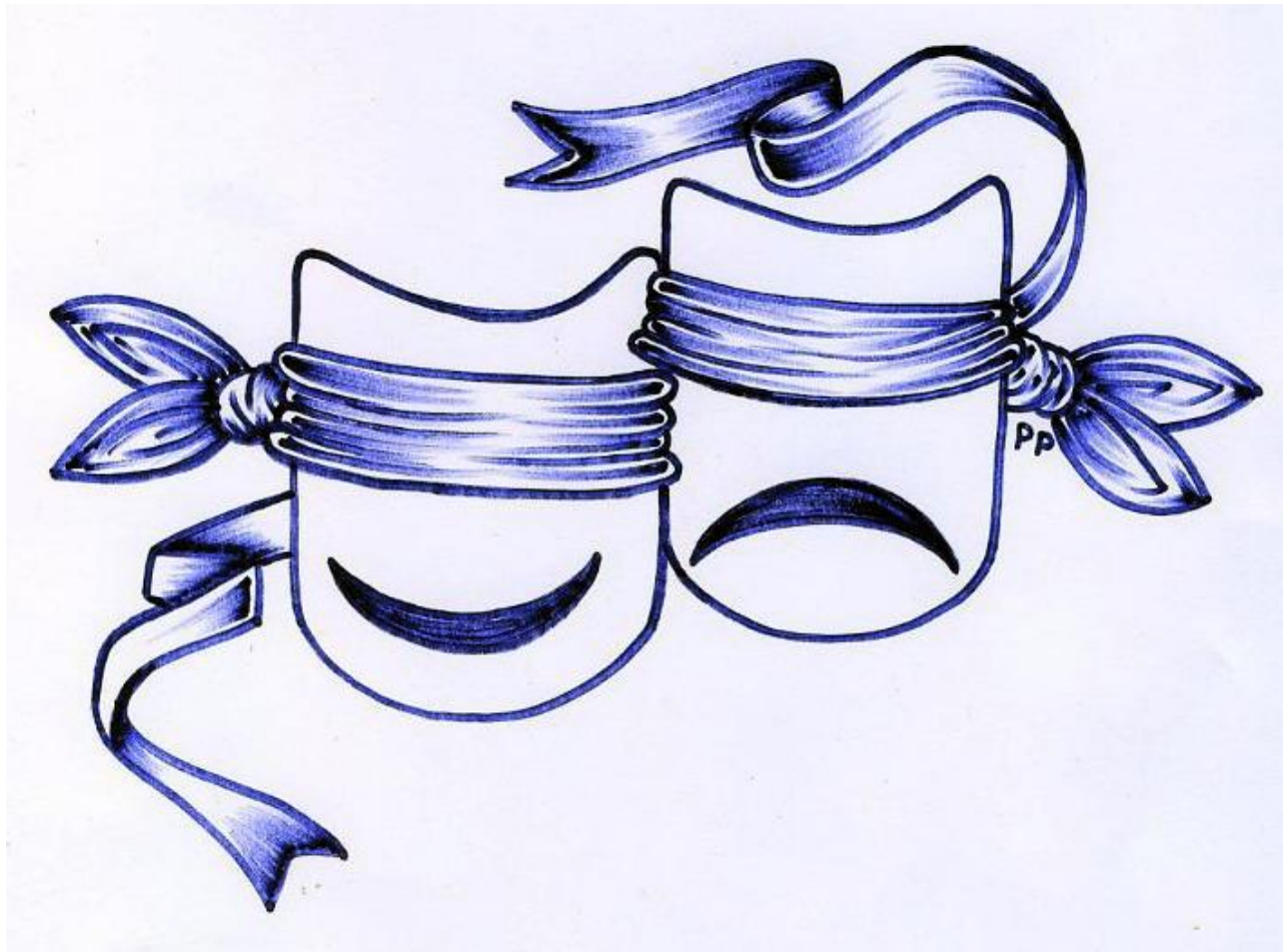


It's hard to see through it every moment, every day

- Kathy Gibson
- From Maryland
- Family Caregiver
- A series of paintings...
- "It's Not Her...It's the Disease!"
- Kgibsonart.com



Challenges in Recognizing Facial Expressions



It's important because...

- ...enough friends fall aside.
- ...first (mis)impressions are lasting.
- ...with the high number of carers in care homes it's easy to be fooled by "Huntington's Disguise."

Current most effective treatment

THERE'S
NO CURE FOR
HUNTINGTONS
DISEASE.

BUT YOU CAN
TREAT IT WITH
UNDERSTANDING

WWW.HUNTINGTONS.IE

What do we tell our communities?



What to include:

- It depends...
- “Huntington’s disease”
- Brain disease
- Both body and mind
- What they will see
- What you can do
- Concisely!





Thanks for making this possible!

