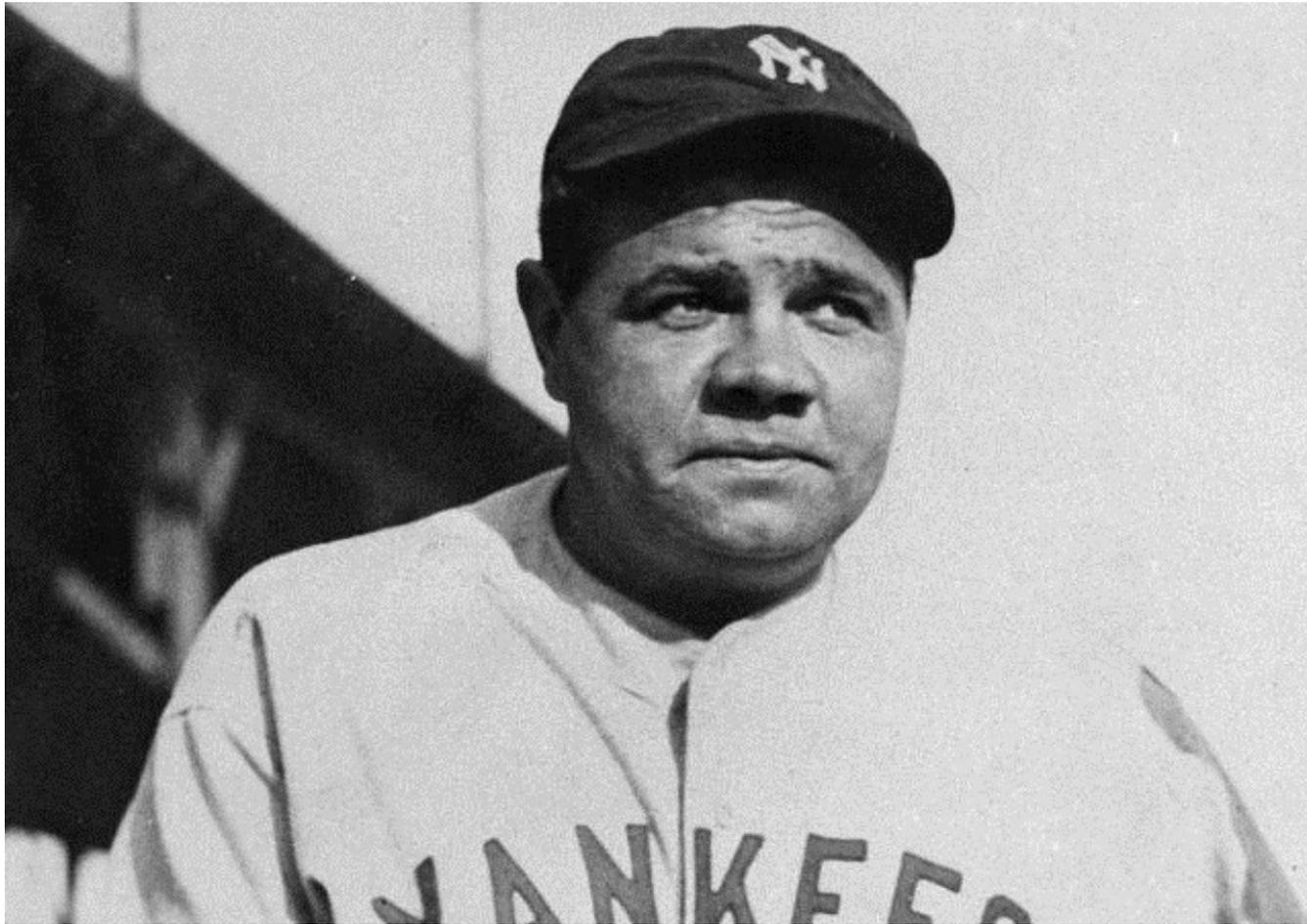


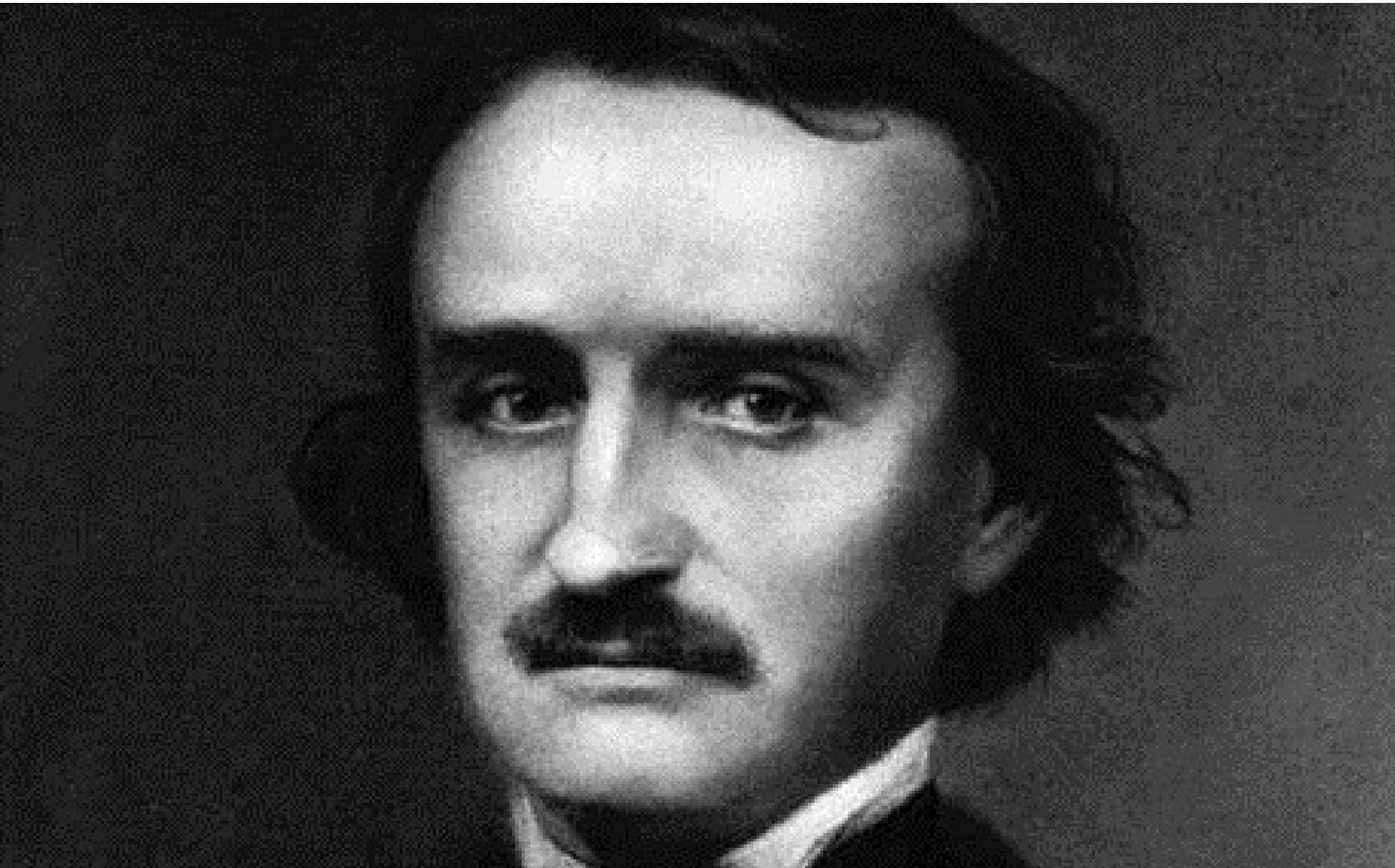


*Welcome to*

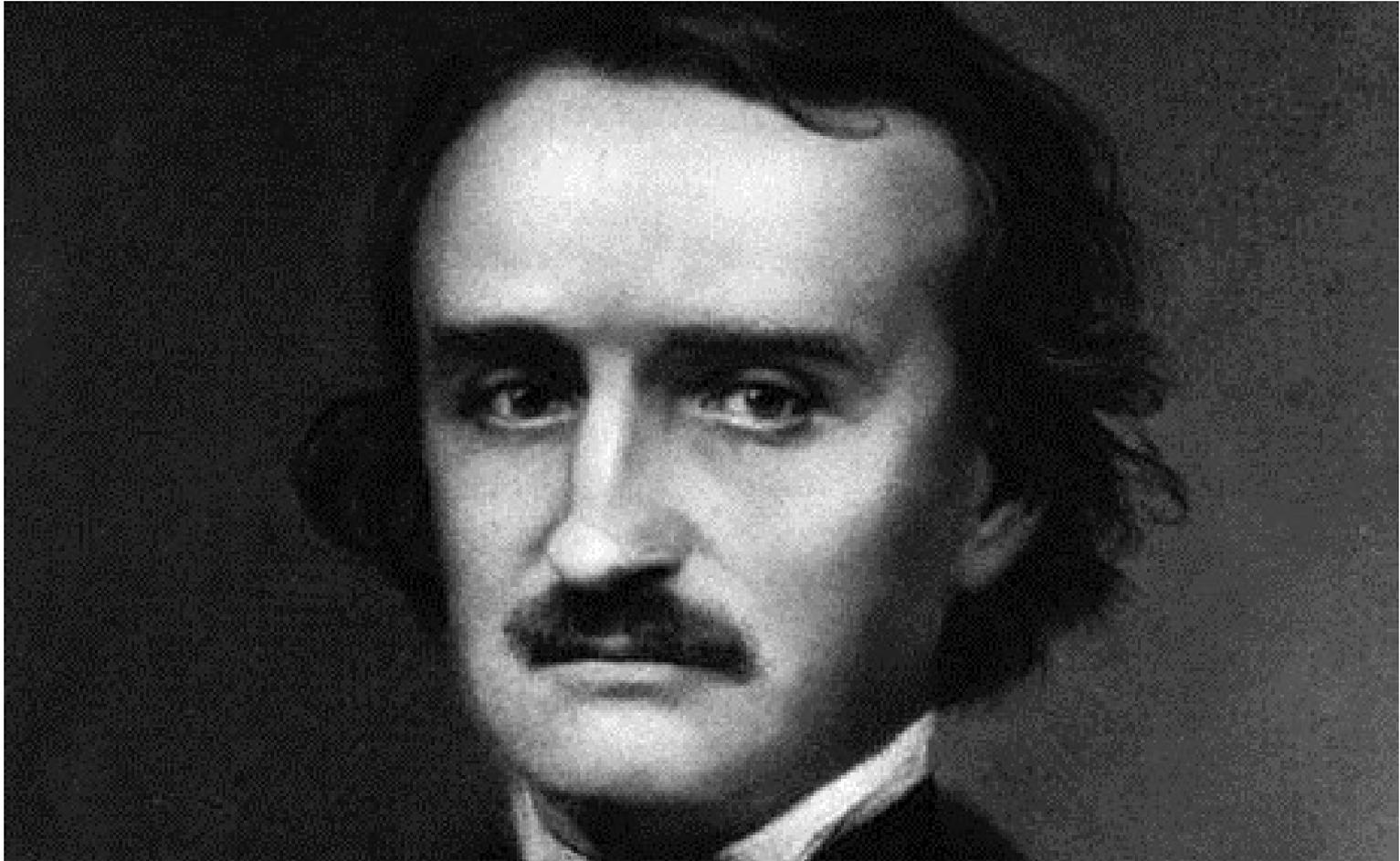
**BALTIMORE**

Baltimore's own...





# Edgar Allan Poe





# “The Raven”

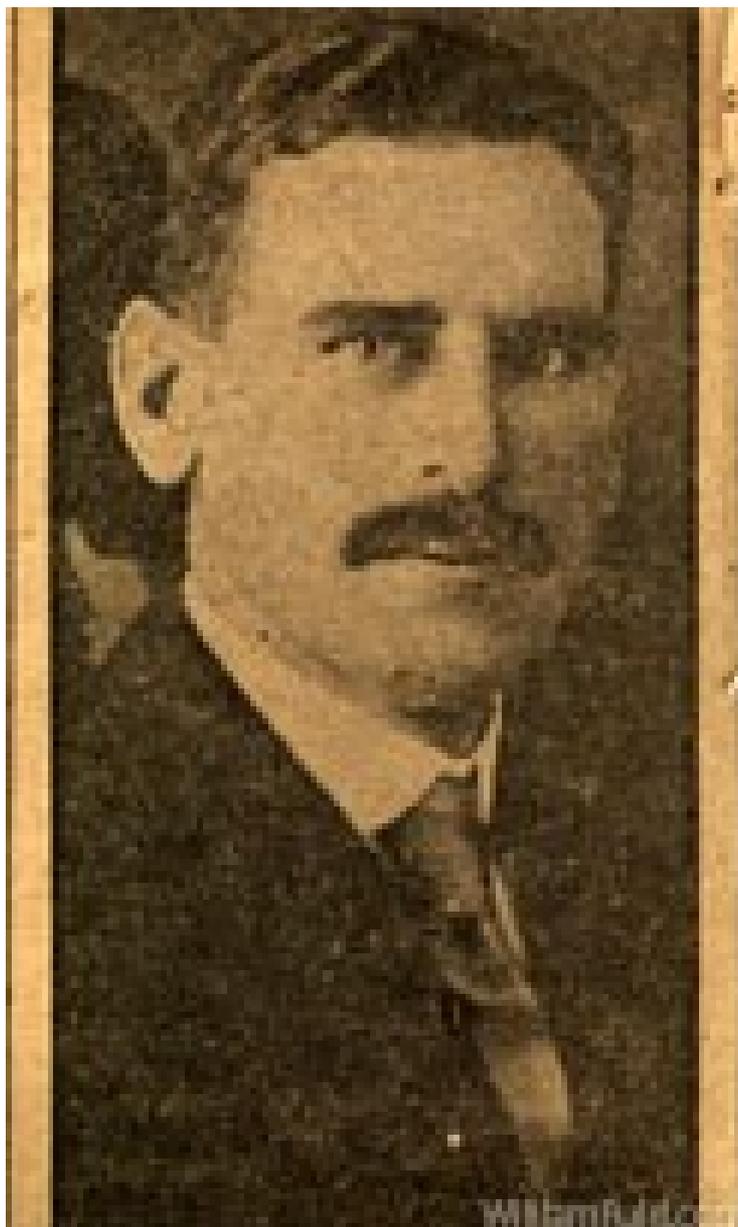
Once upon a midnight dreary, while I pondered, weak and weary,  
Over many a quaint and curious volume of forgotten lore—

While I nodded, nearly napping, suddenly there came a tapping,  
As of some one gently rapping, rapping at my chamber door.

“Tis some visitor,” I muttered, “tapping at my chamber door—  
Only this and nothing more.”

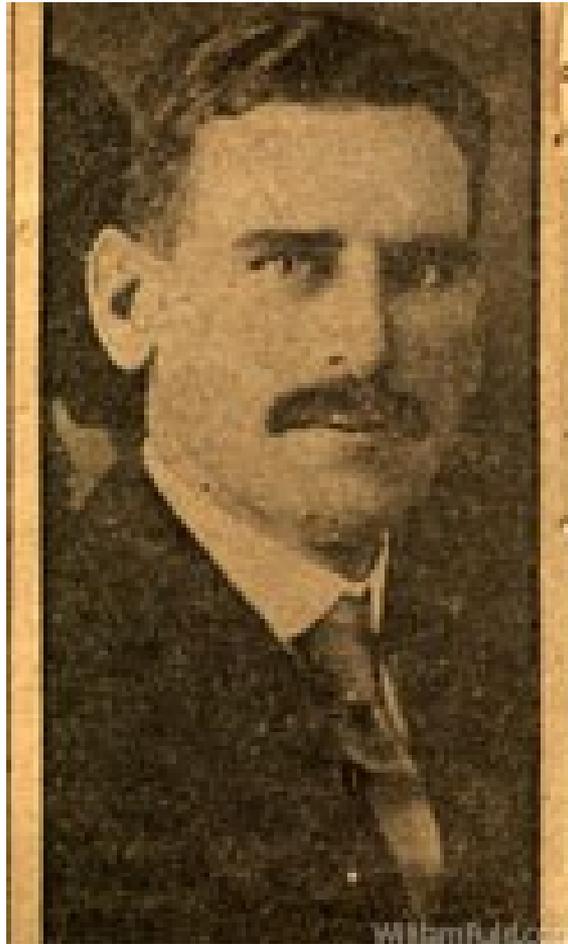
Hence...





William Fuld

1870 - 1927





WILLIAM FELD Talking Board Set

YES

# OUIJA

NO

MYSTIFYING ORACLE

ABCDEFGHIJKLM  
NOPQRSTUVWXYZ

1234567890

GOOD BYE



TRADE MARK OF THE PARKER BROTHERS COMPANY, CHICAGO, ILL. U.S. PATENT OFFICE. REGISTERED IN GREAT BRITAIN AND IN OTHER COUNTRIES. MADE IN U.S.A.

PARKER BROTHERS

Thanks for coming!



Especially for you...Baltimore's own...



Baltimore's own...



And Babe Ruth's from Baltimore!



...and the finest cuisine from my hometown...



# Boston Fruit Slices



# Necco Wafers...New England Confectionery Co.



# Charlestown, Massachusetts





HURRY UP AND WAIT!

# **Thinking About Thinking with Huntington's Disease**

**How it might feel...**

**What we can do...**

## Before we begin, please remember that...

- There are as many different presentations of HD as there are people who live with it.
- However, there are typical signs, symptoms and general similarities that you' ll recognize...
- ...and appear at some point on any one person' s HD road.
- But there are some challenges well beyond the scope of these ideas.

# Preview

- Can we try to see...
- ...what might it **feel** like to think with HD?
- We' ll look at 5 characteristics of thinking with HD.
- We' ll do a few activities that will show us some of these things in ourselves.
- Help us to concretely understand the challenges of thinking with HD.

If you have Huntington's Disease...



## You' ll need...

- ...a pen and paper for our activities.
- Now' s a good time to get them...
- ...and I need help...



We need 3 volunteers!



## My aims are...

- ...***not*** to tell you what you already know.
- ...But to help you see it in a new way.
- ...And to suggest new ways of explaining and teaching it to others.

# Characteristics of Thinking with Huntington's

1. Slower thinking
  2. Recognition is easier than recall
  3. Keeping focus is more difficult
  4. More difficult to organize, plan and sequence
  5. Can't wait
- Yes...

If you want these Powerpoint slides

- There's a sign up sheet right here...



# 1. Slower thinking: What we know

- Fewer cells are working well...
- ...causing ***slower*** processing...
- “Slower thinking”
- Delays in processing information...everything!
- Often not aware of it.



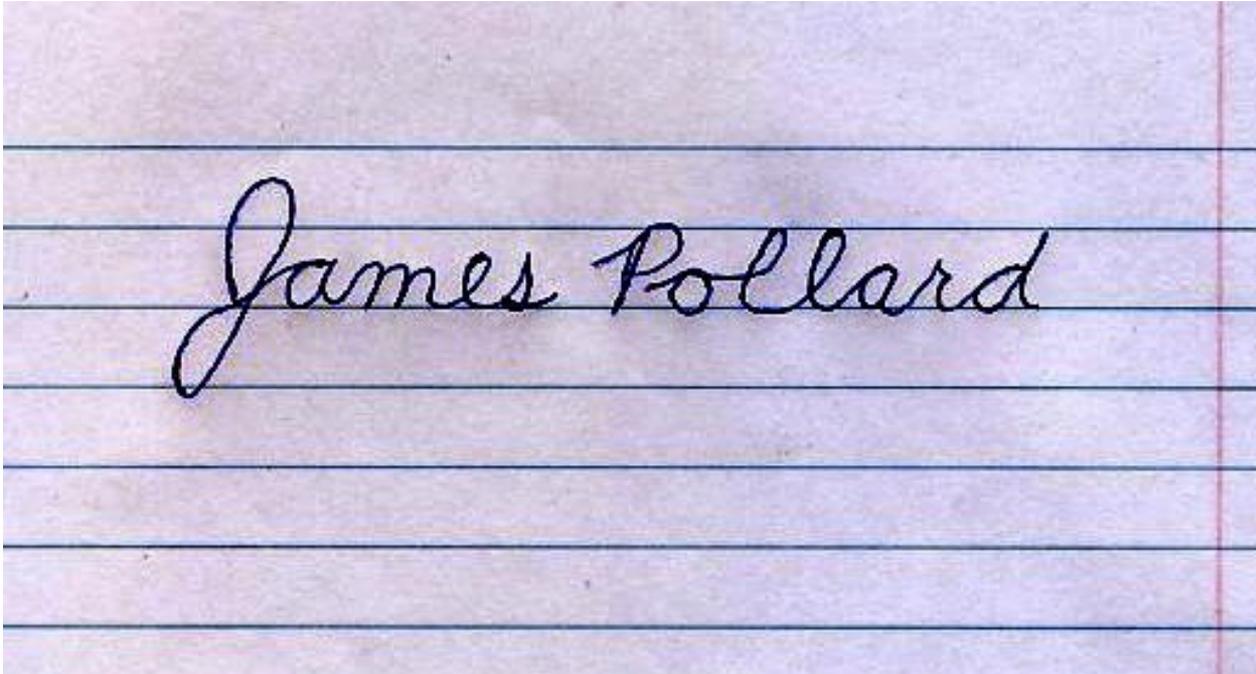
# 1. Slower thinking: How it *feels*

- If you write your name fluently...
- Write your name very slowly.
- 6 letters per minute.
- 1 letter every ten seconds.

# 1. Slower thinking: How it *feels*

- Do you want to continue?
- How did that ***feel***? How would you describe it?
- It's tiring, isn't it?
- It's a time machine!

Here's mine!



James Pollard

# 1. Slower thinking: How it *feels*

- Do you want to continue?
- How did that **feel**? How would you describe it?
- It's tiring, isn't it?
- It's a time machine!
- Concentrating is exhausting, isn't it?
- Distractions come easily.
- How long could I have pushed you?
- Seeds of misbehavior?

# 1. Slower thinking: How it *feels*

- What was unconscious now becomes conscious.
- It was automatic, now you have to pay attention to it.
- “My automatic pilot’ s broken!”
- Something can be so slower that you don’ t do it.
- “He could do it if he really *wanted* to!”

# 1. Slower thinking: When do we see it?

- A story... “*That ’s my Hello!*”
- Delays in processing information...often in conversations.
- Conversations don’ t flow as smoothly
  - Downshifting
  - Comin’ right back at you
- Delays can be predictable and **vary** over time

# 1. Slower thinking: How we can help

- Another story...
- Interrupting slow processing may “Reset the ticker...”
- People like me?  
Aaaarrgghhh!
- Folks report that it’s aggravating and irritating.
- Remember, no timely answer may not mean “No.”

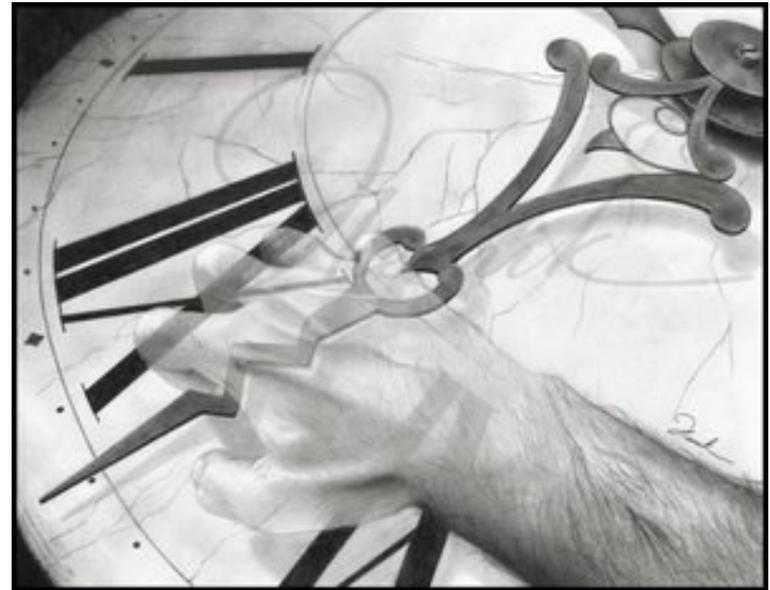


Illustration by shimoda7

Perhaps...

“...I believe I have recognized my earliest HD symptom – which is feeling that there is Saran Wrap on my thoughts for about 20 seconds. My thoughts are there, but they get stuck.”

# “The Rushed Hush”

Trish Dainton

Please give me time to think a while,  
It doesn't help when you cut in;  
Please treasure silence, not fill void,  
Please watch my lips till speech begins.

Please speak to me, I am not deaf;  
Please show me flowers, I am not blind;  
Please take the time to listen more,  
It simply takes a little time.

From *Curse in Verse* by Trish Dainton  
Available from the HDA in the UK

Sadly...

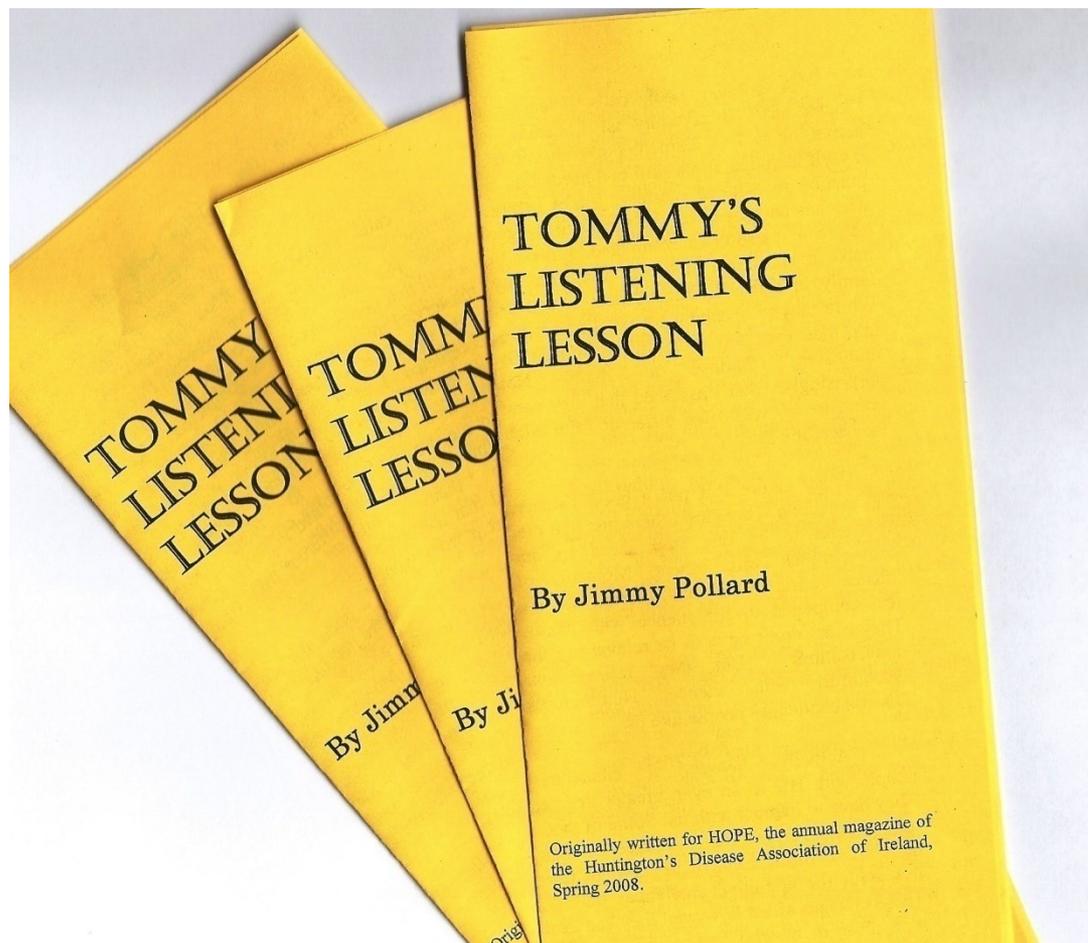


I took a course in speed waiting.  
Now I can wait an hour in only ten  
minutes.

— *Steven Wright* —

AZ QUOTES

Please take one of these with you...



# 1. Slower thinking: How we can help

- Simply wait.
- For some of us, it's so difficult to do.
- Because he thinks slower, **wait**.
- Let's jump ahead to #5...
- 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!?!  
Aarrggghhh!”*



If you've served...



Most seriously, though...



...over the years...

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

Some reminder buttons...for your junk drawer...



# John Canning in North Carolina...



## 2. Recognition is easier than recall.



- Memories? Accessing and expressing them are more difficult.
- There are different kinds of memory.
  - Recognition
  - Recall

## 2. Recognition easier than recall: How it *feels*

- What is recall?
- What is recognition?
- They *feel* different. Let me show you...
- Draw a penny.
- Front? Back? Either side!



Recognition *feels* like this!



## 2. Recognition easier than recall: How it *feels*

- How did recognition feel...
- Easier than recall?
- When you see it and recognize it, it feels like relief.
- It's not uncomfortable, but it is a tiny bit more effort...
- Imagine answering every simple question with just that tiny little bit of extra effort of recalling a penny?

## 2. Recognition easier than recall: When we see it

- When do we see it in ourselves?
- If you miss an test in school, you ask:
- “What kinds of questions were on the test?”

## 2. Recognition easier: How we can help

- Ask an essay question, then wait...
- Ask a multiple choice question, then wait...
- Ask a Yes/No question...
- Just be aware of the kind of questions you ask...
- May not matter in one instance or one day...
- It matters over the years cumulatively...
- Do the best you can until...

### 3. Keeping focus is difficult: What we know

- “Divided attention” is difficult...
- Doing two things at once is difficult...
- People get “locked on” to a topic, they persevere.
- Here’s a well known item on neuropsych tests...
- The “Stroop Task.”

# Our first volunteer!

- Be comfortable!
- You're among friends!

### 3. Keeping focus is difficult: How it *feels*

Say the colors of the word as fast as you can.

RED	GREEN	BLUE	YELLOW	PINK
ORANGE	BLUE	GREEN	BLUE	WHITE
GREEN	YELLOW	ORANGE	BLUE	WHITE
BROWN	RED	BLUE	YELLOW	GREEN
PINK	YELLOW	GREEN	BLUE	RED

### 3. Keeping focus is difficult: How it *feels*

Say the colors of the word, not what the word says, as fast as you can.

RED

GREEN

BLUE

YELLOW

PINK

ORANGE

BLUE

GREEN

BLUE

WHITE

GREEN

YELLOW

ORANGE

BLUE

WHITE

BROWN

RED

BLUE

YELLOW

GREEN

PINK

YELLOW

GREEN

BLUE

RED

### 3. Keeping focus is difficult: How it *feels*

- Did you coach yourself while you did it?
- Difficult?
- Almost kind of confusing?
- An unconscious effort is made conscious.
- ***Feels*** like...

### 3. Keeping focus is difficult: When we see it

- Difficulty doing two things at the same time.
- More difficult to “multi-task.”
- Rub your belly in a circular motion...
- Now...
- Scratch your head.



### 3. Keeping focus is difficult: How we can help

- Go slow.
- Minimize distractions.
- One thing at a time.
- Obvious,
- Simple.
- Absolutely helpful.
- Too easy to think that they are important.
- The profound irony...

## 4. Difficulty organizing, planning: What we know

- Difficulty, organizing, planning and sequencing...
- ...both your thoughts and actions.

## 4. Difficulty organizing, planning: How it *feels*

- Our second volunteer!
- Put on this blindfold!
- Please...



## 4. Difficulty organizing, planning: How it *feels*

- What did you think of ***me***?
- What was your plan?
- How did you feel about the surprise?
- HD is not a loss of vision. But the blindfold makes you become conscious of what is unconscious.
- Again, the changes in thinking with HD makes the once unconscious, now conscious.
- You can do it. But now you have to think about it. Now you must concentrate.
- It *feels* \_\_\_\_\_.

## 4. Difficulty organizing, planning: How it *feels*

- It's more difficult to plan and organize your movement.
- It's also more difficult to plan and organize your thoughts too.
- Things that you can do “in your head.”
- Let me show you!

## 4. Difficulty organizing, planning: How it *feels*

- Our third volunteer!
- We'll do mental arithmetic. It's something that you can do!
- It involves organizing, a sequence of mental activities and creating thinking strategies in your head.
- "Face the audience."
- "Count backwards from 100 by 7s."
- For those watching:
- 100, 93, 86, 79, 72, 65, 58, 51, 44, 37...

## 4. Difficulty organizing, planning: How it *feels*

- How did you do that?
- How did it feel?
- We all know how it feels!
- We feel the same way!
- Try these:

Divide these numbers!

$$669 / 4014$$

$$623 / 17,444$$

$$248 / 43,648$$

$$1,233 / 38,223$$

## 4. Difficulty organizing, planning: How it *feels*

- Do you want to do them?
- But are you able to do them?
- Can you do them fluently?
- It involves organizing, sequencing, doing two things at the same time.
- It feels aaarrggghhhh!
- We avoid it!
- We did it well. Now it's difficult. How does it feel?

## 4. Difficulty organizing, planning: When we see it

- Calculating the tip in a restaurant.
- “Now you know why it takes me two hours to shop for groceries!”
- “Welcome to my world, honey.”
- “Trying to help my son tie his shoes.”
- In pauses in conversations.
- Dressing can become an overwhelming task.
- “It feels like your hard drive is full!”

## 4. Difficult organizing, planning: How we can help

- Routine!
- KISS:
  - “Keep it simple, stupid!”
  - “Keep it short and sweet”
  - “Keep it the same and simple.”

## 5. Can't wait! What we know

- Lack of inhibition is a problem.
- “Jim, you got a haircut!”
- Impulse control is a problem.

## 2. Can't Wait

**I WANT IT:**

**LATER ○**

**NOW**



Can't wait: How we can help

Do it  
**NOW !**



## 5. Can't wait! When we see it

- 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?

## Now let's review these five characteristics...

- First, slower thinking feels like...
  - The fatigue and discomfort of writing slowly?
  - “Is anything fun when you're tired?”
  - The concentration it required?
  - Having to consciously focus on it?
  - Not wanting to continue?

# Let's review all the characteristics...

- Then the easier feel of recognition...



- ...and how it might feel to live every day having to use that tiny little bit of extra effort to answer the 100s of questions you're asked in the course of a single day?

## Let's review the characteristics...

- Then how it's more difficult to stay focused in the face of distractions...
- How difficult it can be to have to switch back and forth in your head?

**BLUE**

**GREEN**

**YELLOW**

**PINK**

**RED**

**ORANGE**

**GREY**

**BLACK**

**PURPLE**

**TAN**

**WHITE**

**BROWN**

## Let's review the characteristics...

- As well as the difficulty to organize, plan and sequence both your thoughts and actions when...
  - Once easy things need as much conscious planning as when you're blindfolded?
  - Having to think hard or all over again after a surprise?
  - And once easy things took as much thinking as counting backwards by 7s?
  - If everyday problems felt like having to actually do those long division problems?

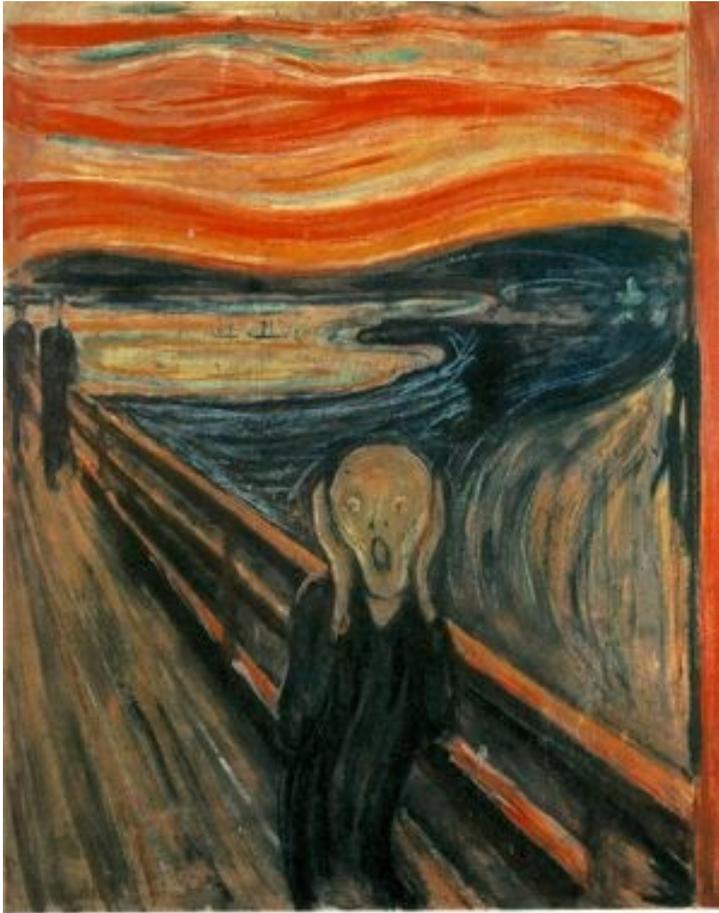
## Let's review the characteristics...

- Take all the ways we without HD feel when we simulate these things...
- Layer them one on top of another...
- Only magnified by Huntington's
- ...and everpresent...every moment..
- And on top of it all...you can't wait!

## Then we ask...

- Could you endure...
- ...with grace...
- ...waiting for anything...
- ...or everything you want?
  
- ***Or might it feel*** like?

Might you *feel* like?



***Scream (Skrik)***

Edvard Munch, 1893

Norway

If you have HD...

“Is it me?”

If you love someone with HD...

“Is it him or is it his HD?”



# Woody Guthrie



# Temper

# Woody

“I wish I could find some well tried system or some good workable scheme or method to just tell you that I am sorry for all the damnable headaches, heartaches, cuts, burns, stings and bruises which I’ve already brought to you in bunches too big and too painful for anybody anywhere to bear up under and to endure them as you have done such a good job of all the way along since we first commenced to lay eyes on one another.”

“I hate this short temper of mine several times worse than you hate the damn thing. I never did deceive or fool myself that I’d ever find any close companion that had either the foolishness or the wisdom about them to understand it and to overlook it, that is, excepting my own pore damn self, and me only because I’ve got this job sorta forced into my hands.

# These characteristics contribute to conditions...

<b>Characteristics...</b>	<b>...Conditions</b>
<ul style="list-style-type: none"><li>• Slower thinking</li><li>• Recognition is easier than recall</li><li>• More difficult to change topics</li><li>• Difficulty organizing and planning</li><li>• Can't wait</li></ul>	<ul style="list-style-type: none"><li>• A narrow focus on what's next</li><li>• Apathy</li><li>• Irritability</li></ul>

## Condition: Narrow focus on what's next

- Might we not, through our behavior, be saying...
- So much information...too much information!!!
- Like fighting off overload...
- From all the characteristics...
- “OK, just one thing at a time. *Please!*”

## Condition: Apathy and Irritability

- Apathy is the absence of emotion, passion or excitement...
- ...especially for things that once interested you.
- Sort of a general “Whatever...”
  
- Irritability is an impairment controlling or modulating:
  - Impulses to do things
  - Especially expressions of emotion, very often anger.
  - Folks with “short fuses.”

## Conditions are related to cognitive changes...

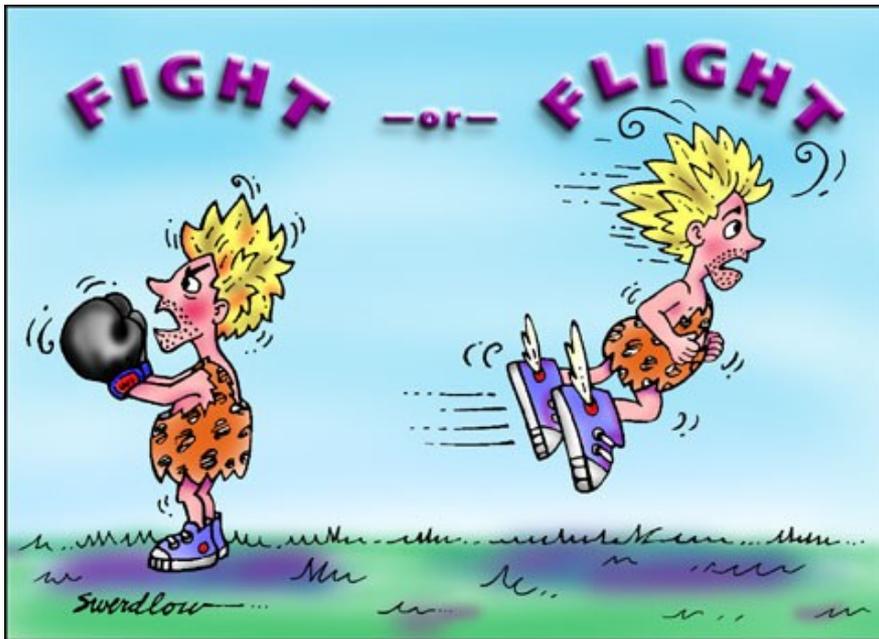
- “Many, if not most, people with HD often experience less well defined, non-specific changes in personality and mood, such as irritability, apathy...”
- “Most of these...problems are believed to be related directly to the central nervous system injury caused by HD.”

*A Physician's Guide to the Management of Huntington's Disease, 2<sup>nd</sup>*

Edition

# The Stress Response...

- Fight or flight?
- You might think of Flight as Apathy and...
- Fight as Irritability



# Universal approaches

<b>Condition</b>	<b>How we can help</b>
Narrow focus on what's next	<ul style="list-style-type: none"><li>• Go slow; one at a time.</li><li>• Respond timely; wait.</li><li>• Don't reset the ticker!</li><li>• Ask multiple choice questions.</li><li>• Routine in your day.</li><li>• No surprises!</li><li>• Recognize and anticipate to accommodate them.</li></ul>
Apathy	
Irritability	

# What does it *feel* like to think with HD?

We can only speculate...

...based on neuropsychology.

...based on how we feel when we try to imitate or simulate it.

...reports from people with HD.

...comments about this from people with HD.

# Living with the cognitive changes of HD...

- Finding relief...
  - ...from this moment-to-moment struggle...
  - ...over days, years and decades...
  - ...is the primary challenge of living with Huntington's Disease.
- Understanding these changes in thinking...
  - ...and changing how we live...
  - ...and how we communicate...
  - ...will impact their struggle...
  - ...and is a ***profound act of love.***

# Current most effective treatment

THERE'S  
NO CURE FOR  
HUNTINGTONS  
DISEASE.

BUT YOU CAN  
TREAT IT WITH  
UNDERSTANDING

[WWW.HUNTINGTONS.IE](http://WWW.HUNTINGTONS.IE)

I have some “cheat sheet” cards for you...



Sometimes it's hard to see it through their eyes...



And if you're interested, this is in book form...



I always close with this poem...

- Leon Joffe
- Pitta, his wife
- In South Africa...

Know Then

Leon Joffe

You surprise me every day

Your fighting spirit

Your vision and its ability to draw me forward with you

Your loveliness even as you plunge through the hard core  
of the future.

You achieve what others dare not even dream about

You know no barriers to the universe

You are my dreamer, my leader

With you I am greater than myself.

Know Then

Leon Joffe

With you my perpetual fear, carried like a rock, is turned to  
water

To drain away through the tunnel of your laughter and  
courage.

This day we face together another challenge;  
I here too distant to do more than love you.

Know Then

Leon Joffe

I will myself to weakness

That my strength may add to yours.

I will myself to passivity

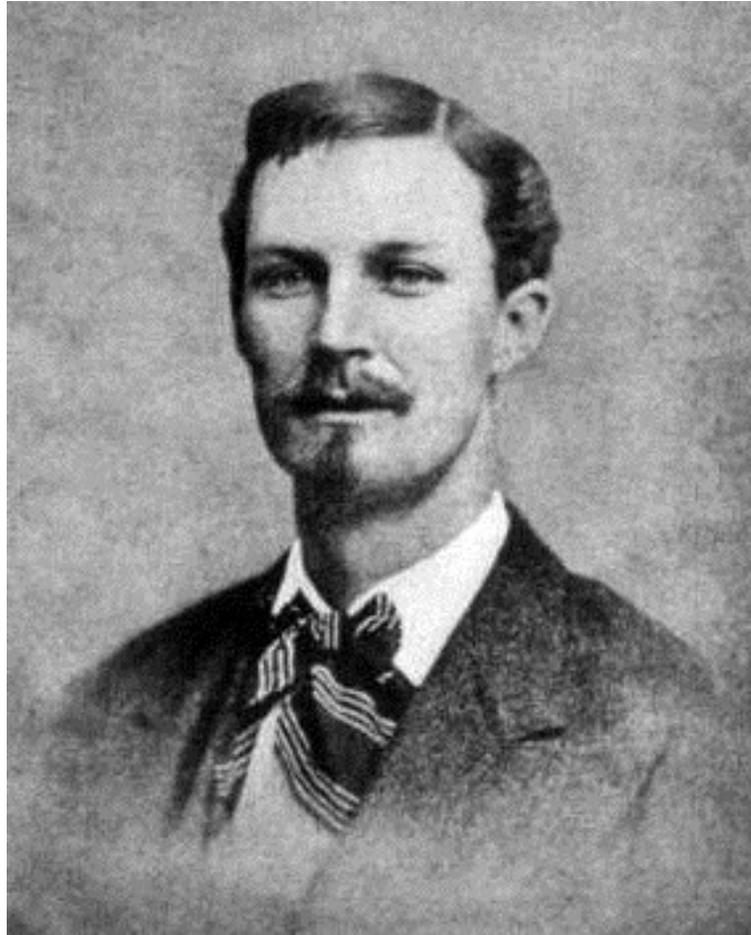
That your actions may shame and humble all like me.

Know then how much I admire you;

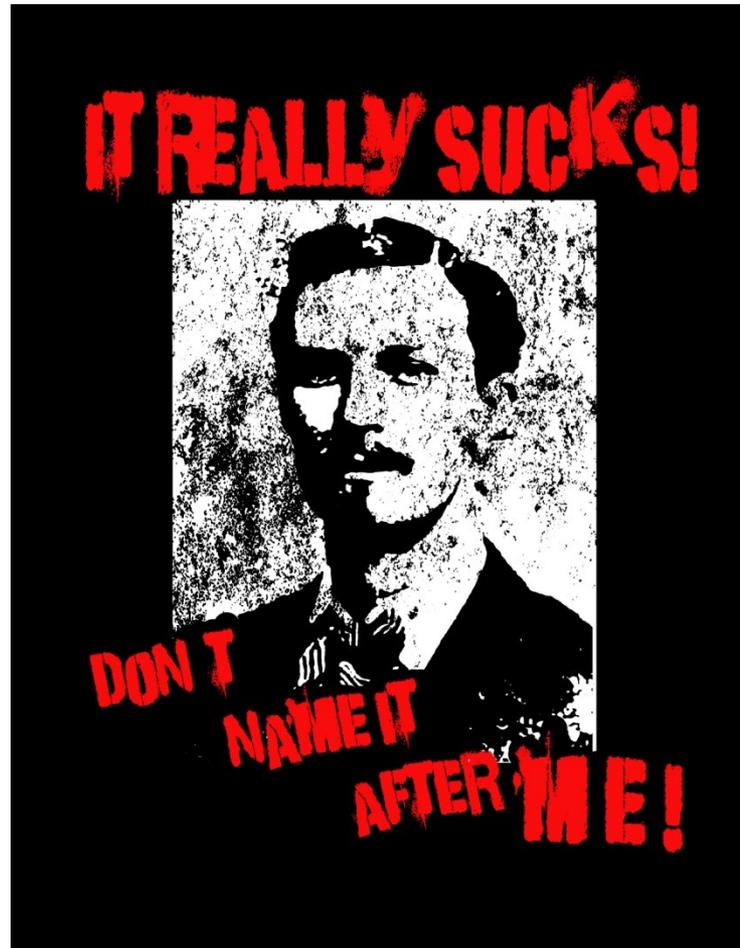
And much more than that

Love you

I leave you on a lighter note!



If George were with us today...



There's one with your cards!

**Huntington's Sucks!!!**

That's why we're doing something about it, standing together with scientists and docs! cs!

**Huntington's Sucks!!!**

That's why we're doing something about it, standing together with scientists and docs!

That's why we're doing something about it, standing together with scientists and docs!

Stay in touch!!!

**HUNTINGTON'S**



Thanks for making this possible!



**CHDI**

**FOUNDATION**

## If you'd like a guest speaker...

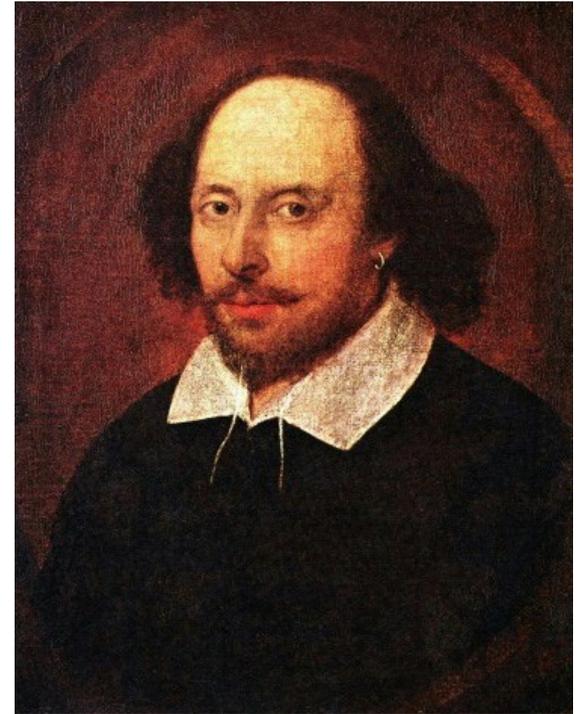
- ...I'm willing to do "Hurry Up & Wait!" at *your* support group or Education Day.
- The CHDI Foundation fully supports my work.
- There's no cost to you, your group or chapter.
- I welcome the opportunity!
- Simply ask me!
- I also welcome opportunities to speak about Enroll-HD.

Thank you, volunteers!

WE L  VE  
OUR VOLUNTEERS

# William Shakespeare

“What sport shall we devise here in this garden,  
To drive away the heavy thought of care?”



Let's ask the Ouija Board...



Let's ask the Ouija Board...



# A Talent Show!!!!



Thank to you for having me here with you today!





HURRY UP AND WAIT!

## If you'd like a guest speaker...

- ...I'm willing to do "Hurry Up & Wait!" at *your* support group or Education Day.
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