

# HNF1B: TEARS & JOY



Grant & Amy King  
Support Day, Sept. 2018

## What's wrong with me?

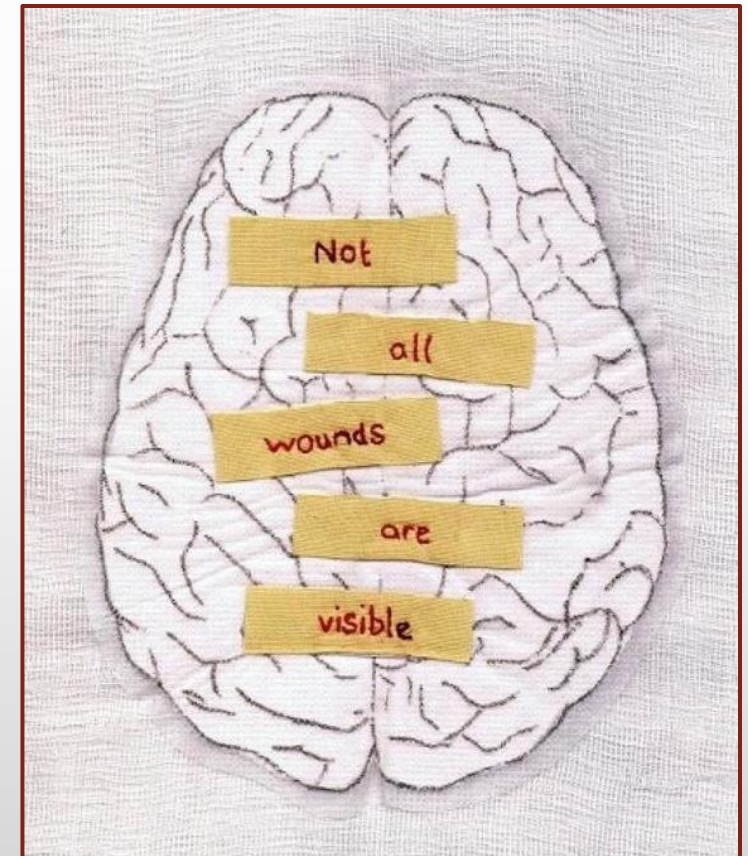
- HNF1b mutation
- Stage 4 CKD
- MODY 5
- Obstructive azoospermia
- Kidney stones
- Liver
- + Thyroid / Para

## What's right with me?

- Married for 18 years
- X3 adoptive children
- Lecturer in mental health nursing
- Carer for parents
- Photography, poetry & music
- Admin for HNF1b Facebook page

# A patient's journey...

- 2012 – *Have you tried Google?*
  - *The Patient journey*
- 2016 – *HNF1b: A Family Affair*
  - *Raising a child with HNF1b mutation*
- 2018 – *HNF1b Tears and Joy*
  - *The emotional impact of ill health*



# The Bad News

- Research evidence consistently demonstrates that people with long term conditions are two to three times more likely to experience mental health\* problems than the general population (Naylor et al 2012).
- Mental health problems such as depression are much more common in people with physical illness. Having co-morbid physical and mental health problems delays recovery from both (Department of Health 2011).
- Being physically ill, particularly on a chronic basis, often has an impact on mental health and psychological wellbeing. Despite these obvious connections, many individuals do not receive care that addresses both their physical and psychological needs (NHS Confederation 2012).

# The Good News

- *“It is the very transience of life that enhances love. The greater the risk, the stronger grows the attachment.”*
  - *Colin Murray Parkes*
- *“Normality is a paved road. It’s comfortable to walk, but no flowers grow on it.”*
  - *Vincent Van Gogh*
- *“We are stronger in the places we have been broken.”*
  - *Ernest Hemingway*
- *“Sickness bring out the essential characteristics of a [person].”*
  - *Felix Frankfurter*

# Issues, answers and benefits

- Autonomy
- Betrayal
- Frustration
- Overthinking
- Sacrifice & Loss
- Vulnerability
- Worn down & Worrisome
- Creativity
- Empathy
- Experience
- Knowledge
- Support
- Openness
- Realism

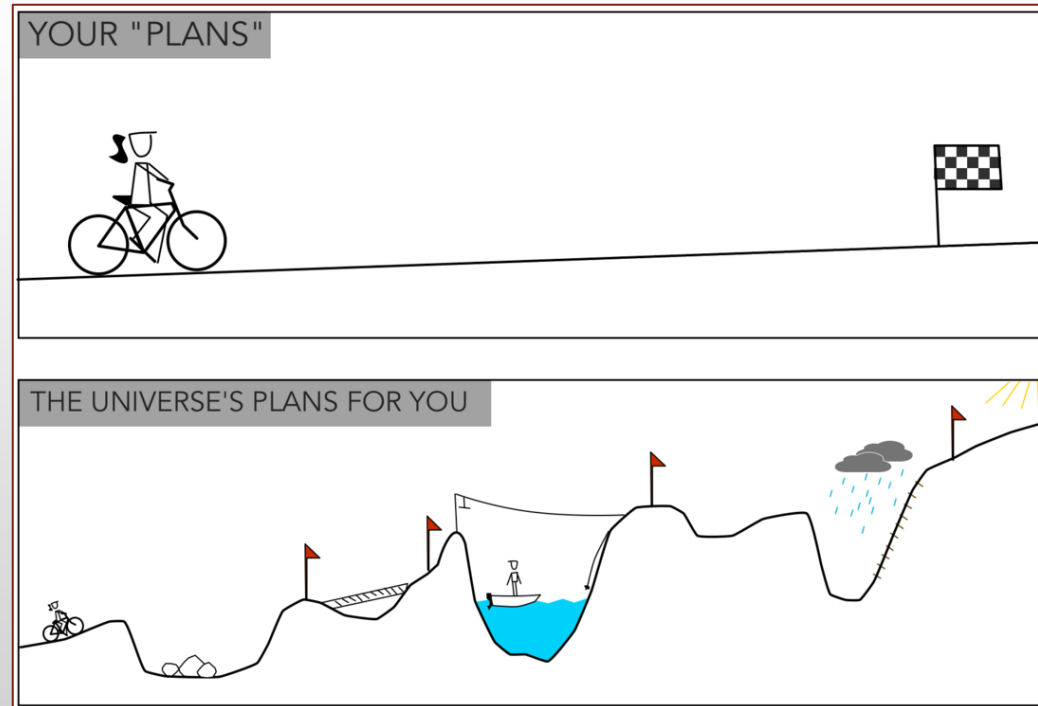
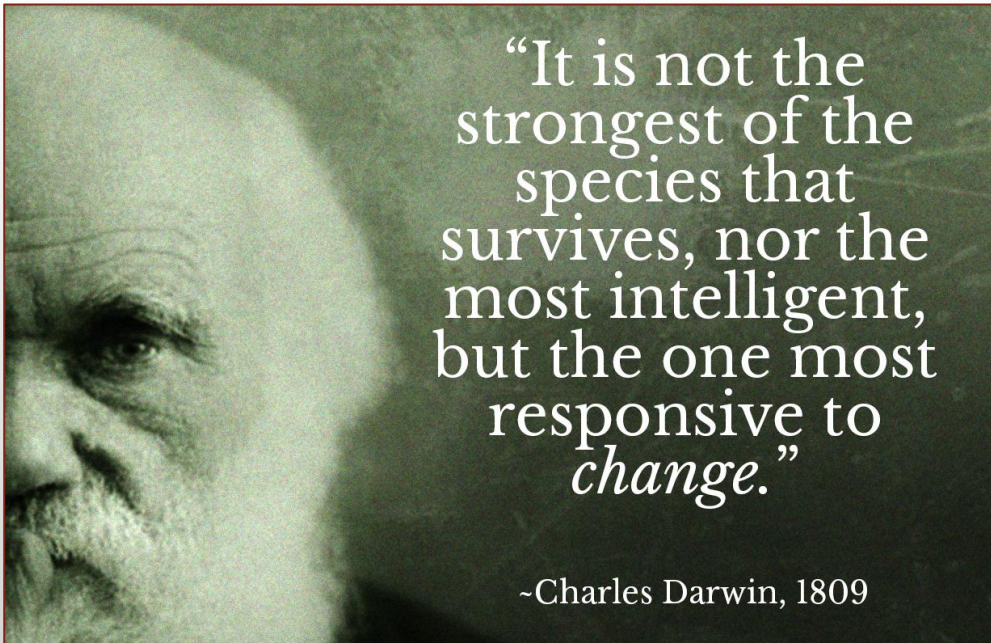
HOW WE  
WANT  
GRIEF TO  
WORK



HOW GRIEF  
ACTUALLY  
WORKS



CRYING IS  
OKAY HERE



# Resources

- <https://www.mentalhealth.org.uk/a-to-z/l/long-term-physical-conditions-and-mental-health>
- <https://www.rcpsych.ac.uk/healthadvice/parentsandyoungpeople/parents/carers/chronicphysicalillnesses.aspx>
- <http://www.nhsconfed.org/-/media/Confederation/Files/Publications/Documents/Investing-in-emotional-and-psychological-wellbeing-for-patients-with-long-term-conditions-16-April-final-for-website.pdf>