

It is only through the
eyes of others do
you see yourself.

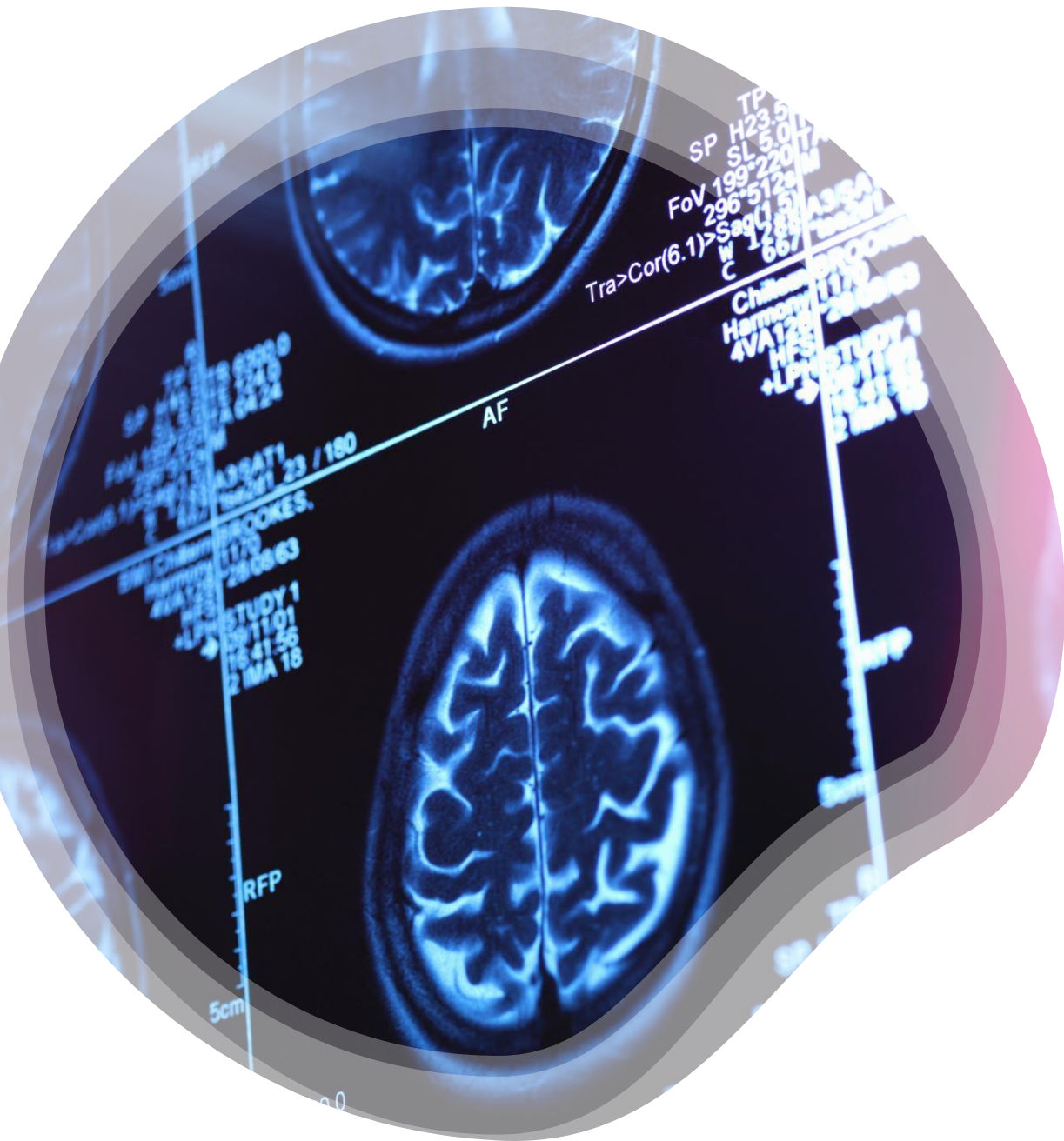
anonymous

Understanding the Psychology of the Keratoconus Patient

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Keratoconus Personality (chronic eye disease)


- Less conforming
- More passive aggressive
- Paranoid
- Hypomanic
- Disorganized patterns of thinking
- Higher substance abusers

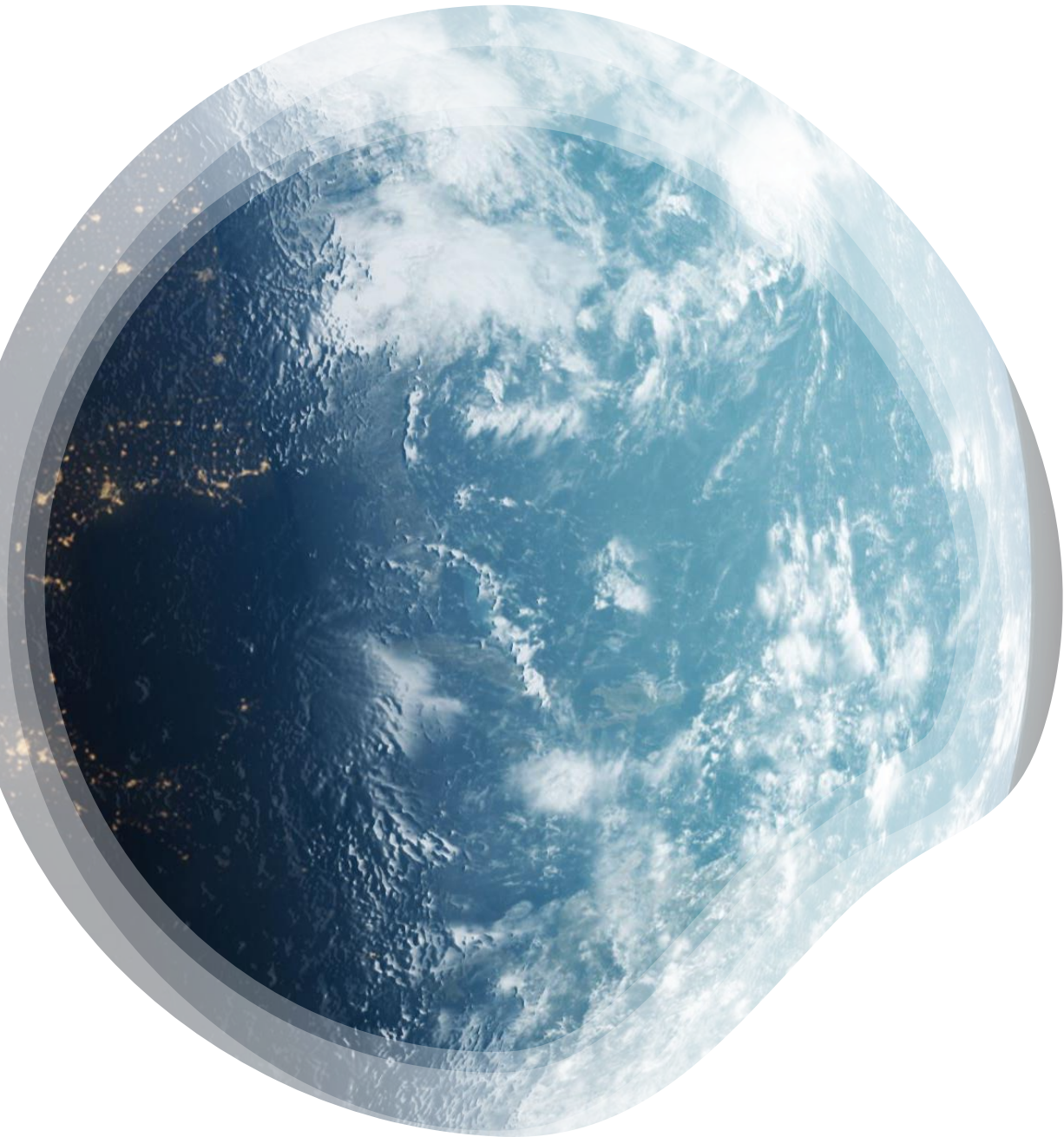


“no one understands I can't see”



Life Changing Event

- Individuals are required to review and modify assumptions about the world that have been built up over many years
- 



Life Changing Event

- A familiar world becomes unfamiliar causing feelings of:
 - Anxiety
 - Fear
- Which may:
 - Cloud judgment
 - Impair concentration and memory



Life Changing Event

- Grief arises from an awareness of a discrepancy between a world ‘that is’ and a world that “should be.”



Stages of Grief

- Shock
- Anxiety
- Bargaining
- Denial
- Mourning
- Depression
- Withdrawal
- Internalized Anger
- Externalized Anger
- Acknowledgement
- Acceptance
- Adjustment-
Adaptation

- 
- The slide features decorative curved lines in shades of green and blue, positioned in the top-left and bottom-right corners. The main content is a single bullet point centered on the page.
- 35% of adults with recent onset of vision impairment experience symptoms of clinical depression.



Psycho-social Transition


- The diagnosis causes fear, anxiety and loss of confidence.
 - Numbness
 - Loss of concentration/ memory

Psycho-social Transition

- May initially resist change
 - Alternative options/ diagnosis



Psycho-social Transition

- Tries to make sense of what has happened
 - Search for information
 - Internet
 - Spiritual
- 

Psycho-social Transition

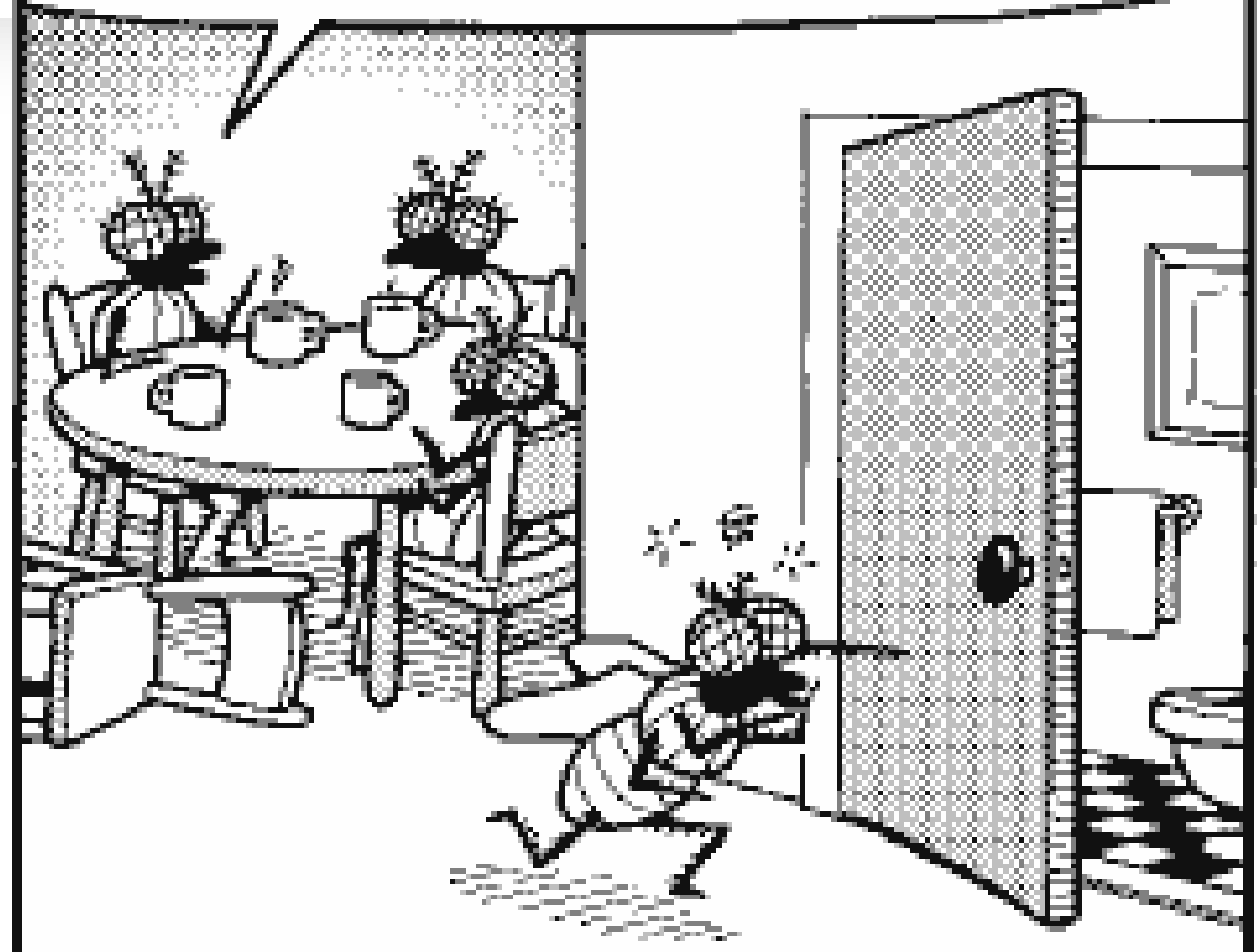
- Rebuild and accept a new model of the world.

off the mark

by Mark Parisi

www.offthemark.com

WE DON'T GO OUT MUCH...FOR
WHATEVER REASON, BUCKY NEVER
QUITE ADJUSTED TO COMPOUND EYES



Chronic Sorrow

- Cyclic Sadness
 - Feeling of sadness or guilt resurface at times of
 - Crisis events
 - When the disease is brought to the forefront
 - External and Internal Stimuli



Chronic Sorrow

- Trajectory of Illness
 - Events leading up to illness
 - What is happening now
 - What may or may not happen in the future
- Growing enormity of what happened and inability to change it

Family Factors






Marital

Emotional Cognition

- Spouses affected by partners vision loss
- Increased physical support by the non-disabled spouse may be counter balanced by an increase in emotional support or appreciation by the ill spouse.



Emotional Cognition

- Chronic illness may have greater impact on marital satisfaction on the non-disabled partner.
- 



Parental



Parent Stressors

- Child's future
- Day-to-day care
- Exacerbation of the illness
- Disease severity
- Inability to protect child from harm
- Loss of freedom, spontaneity, control



Parental Stressors

- Parental demands:
 - Treatments
 - Monitoring
 - Care giving activities
 - Maintenance of family integrity
 - Insuring financial stability



Parental Stressors

- Parental demands may lead to:
 - Depression
 - Fewer social interactions
 - Restricted career mobility
 - Frustration
 - Feelings of distress



Parent Stressors

- Mothers request:
 - More emotional support from spouses
 - More informational support from health professionals.



Coping Strategies

- Managing daily care
- Educating others about illness and care
- Meeting normal developmental tasks
- Managing feelings
- Support network
- Participating in religious activities
- Giving meaning to the illness

Professional Responsibility

We can't change how patients act

We can change how we react



Professional-Patient Relationships

- Professional authority
- Moral authority
- Empathic authority

Professional Authority

- Derived from doctors' actual or perceived scientific competence.
- Diagnosis and treatment options



Moral Authority



"If you allow us to paint your head black,
we can install a solar-powered pacemaker."

- Paternalism
- Based on the concern for the individual patient
- Clear-cut recommendations



Empathic Authority

- “ When someone really hears you without passing judgment on you, without trying to take responsibility for you, without trying to mold you, it feels darn good”

Marshall Rosenberg

Empathy

Respectful understanding of what others are experiencing.

Empathy

- Frustration results when someone needs empathy and the doctor assumes they want reassurance or “fix-it” advice.



“How come every time she tells me ‘it’s for your own good,’ it makes me feel *bad*?”

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Don't' Just Do Something
Stand There!



Never Put Your “BUT” In
The Face Of An Angry
Patient!

Empathy

- Intellectual understanding blocks empathy
- Ask before offering advice or reassurance

- Empathetic listening actually saves time!



Empathy

- How to give Empathically
 - Para-phrase what the patient is saying
 - Make eye contact
 - Look for the feeling behind statements
 - Don't ask a series of question that require informational answers.



Empathy Burn-out



Empathy Burn-out

- Symptoms:
 - Physical
 - Emotional
 - Work decline

Empathy Burn-out



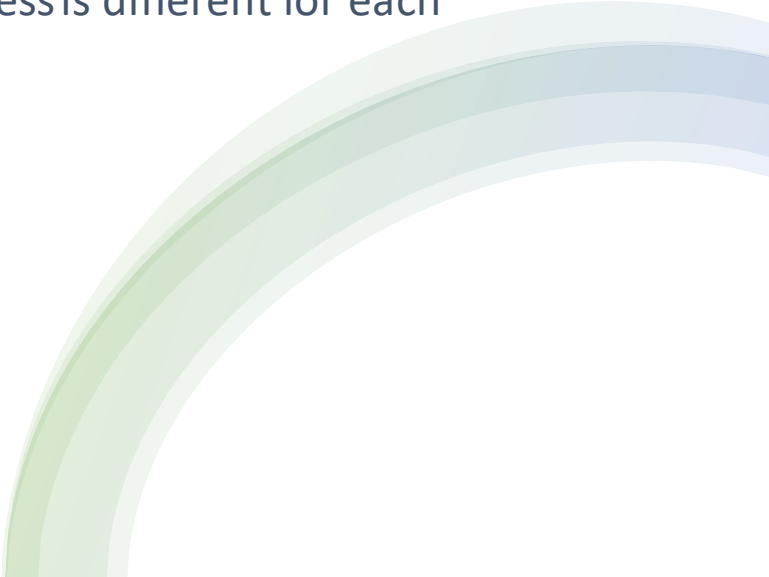
- Fixes:
 - Communicate
 - Empathy not sympathy
 - Watch what you watch
 - Attitude

Vision Rehabilitation Team

- Eye care specialist
- Nurses/ technicians
- Low vision specialist
- Teacher of students with visual impairments
- Low vision educator
- Orientation & mobility specialist
- Psychologist
- Rehabilitation teacher
- Vocational rehabilitation counselor
- Occupational therapist
- Physical therapist
- Technology consultant
- Social worker
- Gerontologist



Proactive Model of Care

- Be aware and sensitive to grief cycle
 - Give “permission” to grieve and reassure grief is normal and acceptable
 - Acknowledge feelings of loss, grief and fear in context of world “that should be” and “world that is”
 - Understanding adaptation process is different for each individual
- 

Proactive Model of Care

- Be aware of cyclic sorrow
- Encourage them to talk about their feelings
- Explain why it may be difficult to retain information
- Give written information
- Give assurance that education will be repeated after initial shock of diagnosis has passed

Proactive Model of Care

- Acknowledge achievements to promote confidence.
- Arrange for social and economic support services
- Refer/coordinated care for conditions beyond your scope of practice





- Listen without judgment
- Para-phrase what you are hearing
- Take care of your emotional self

Proactive Model of Care

Thank You

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