



UZ  
LEUVEN



# Significance of a holistic treatment of CF patients – multidisciplinary team, integral care for patients and their family through their life time.

Trudy Havermans

UZ  
Leuven

Herestraat 49  
B - 3000 Leuven

[www.uzleuven.be](http://www.uzleuven.be)  
tel. +32 16 33 22 11

UNIVERSITY HOSPITALS LEUVEN

- Relationship
- Familial background
- Parenting skills
- Parental MH

Social skills

- Community
- Religious background
- Financial situation
- Living circumstances

GOOD LUCK?

CF symptoms,  
treatments...

CF patient

Social support  
Society  
Health care

BAD LUCK?

- Personality
- Character
- Resilience
- Optimism/pessimism

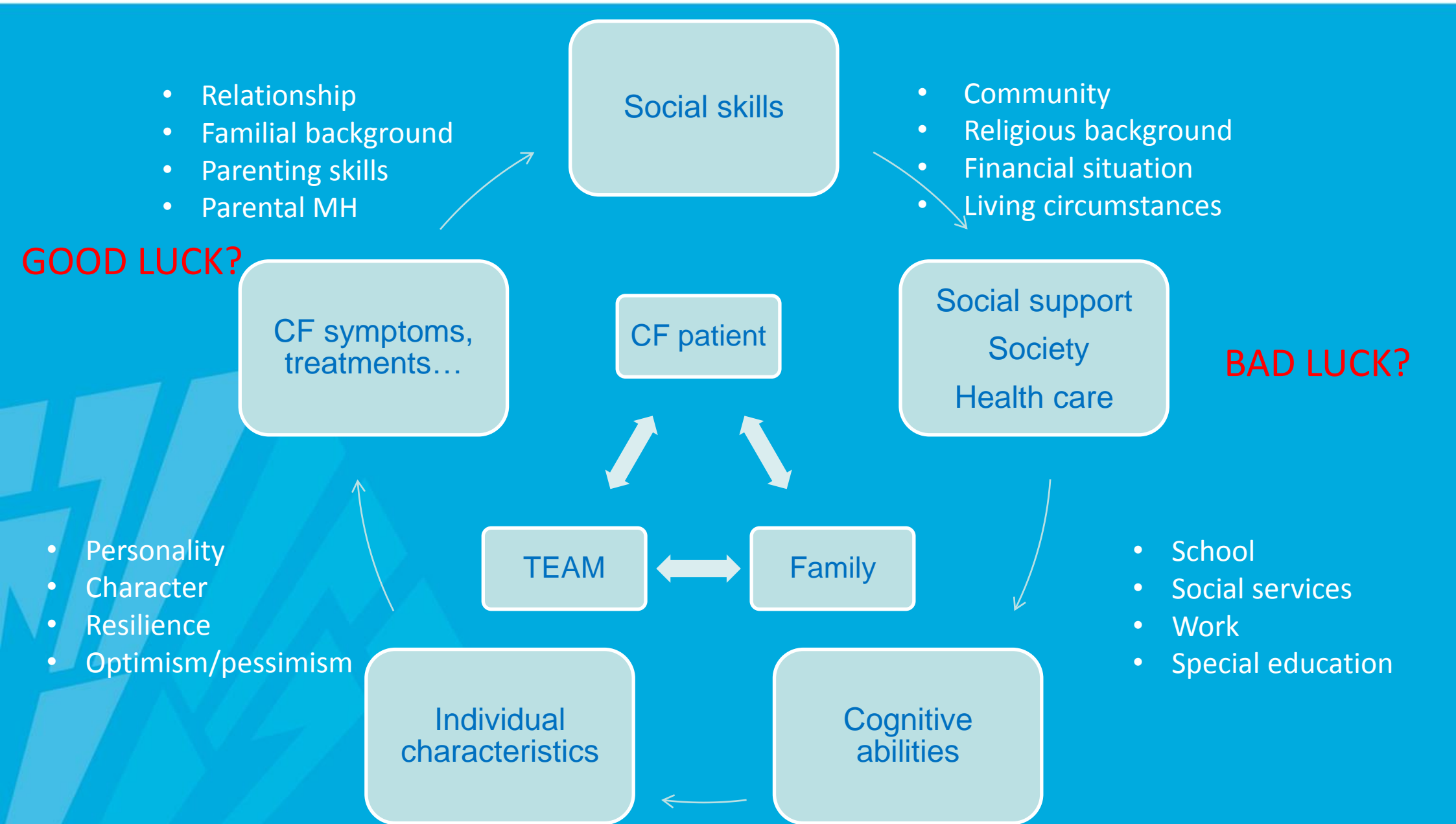
TEAM

Family

- School
- Social services
- Work
- Special education

Individual  
characteristics

Cognitive  
abilities



# Holistic treatment of patients

- Holistic therapy in a **medical setting**:  
Addressing the **whole person**, including their
  - **physical**
  - **mental**
  - **emotional health** whilst taking **social factors** into consideration.
- A multidisciplinary team: to address an individual as a whole person, rather than as someone who is sick.
- **Holistic medicine philosophy: optimal health by gaining balance in life.**

# What is the best management for patients with CF ?

A European consensus on

- Framework for the CF centre
- Best practice guidelines
- Quality management in CF

# The multidisciplinary team

- Respiratory pediatrician/pulmonologist
- Clinical microbiologist
- Medical support from trainee(s)
- Clinical nurse specialist
- Specialist physiotherapist
- Specialist dietician
- Clinical psychologist
- Social worker
- Pharmacist
- Clinical geneticist
- Secretarial support
- Database coordinator

## Some principles for CF centres

- Staff and facilities for comprehensive and holistic care of CF and CF associated complications
- Fast access to routine and emergency care and advice
- Review
  - at least 3 monthly, more often as required
  - yearly full review of medical, physio, diet, psychosocial aspects
    - with written treatment plan
    - together with the patient and caregivers

Infant ...

... toddler

## 'Normal' life

- Attachment
  - Trust
  - Safety
  - Interaction
- Getting to know the world

## + CF

- Diagnosis
  - Symptoms
  - Start treatment
  - Hospitalizations
  - CF team
- 
- Impact on parenting



- **Parents**

- sadness
- guilt
- desperation
- loss of control
- anger

- Information about CF
- Integrate CF in the family
- Involve siblings

**Time – plenty of time**

## CF and impact on parenting

- Eating
  - obsession
  - mealtime behavioral problems
- Overprotection (social isolation)
- Few symptoms
  - low adherence
  - lack of routine
- Parental anxiety and depression  
→ threat to attachment

- Story of diagnosis
- Context
- Empathy
- Illness representations:
  - cause, consequences, controllability, curability
  - personal experiences
- Education about CF
- Use of hope
- Reconstruct future
- Identify coping styles
- Stimulate coping: optimism, hopefulness
- Seek help, refer

All members of the MDT need to deal with these fears

# From toddler ..... to pre-schooler

- Toilet training
- Eating
- Sleeping
- LANGUAGE
- PLAY!
- Socializing - RULES
  
- Will development
  - Stubborn, 'terrible two's'

## + CF

- Blood taking, throat swabs
- Nebulizer, physio, PEP ...
- Pills....

## + CF

- Parents responsible
- Treatment takes time
  - ‘Don’t want to’
  - ‘Toothbrush rule’
  - ‘Normalisation’
- Age appropriate explanation

- **Threat: insecure child raising**
- Projection of own fears
- Isolation from other children
- Strict hygiene rules, restriction play

• • • •

**Primary school age (5 up)**

- School and learning
- Social skills
- Free play ->play to rules
- Education, self-discipline
- Skills, arts and crafts, ....

## Independence

+ CF

- Awareness of being different
- Age - appropriate learning about CF
- Self care, wanting to do things, able to do things
- Routine and adherence

## Met mucoviscidose op jullie school



leerlingen



- Help and education at school
- Stimulate normal interaction!
- Self-care
- Involve siblings

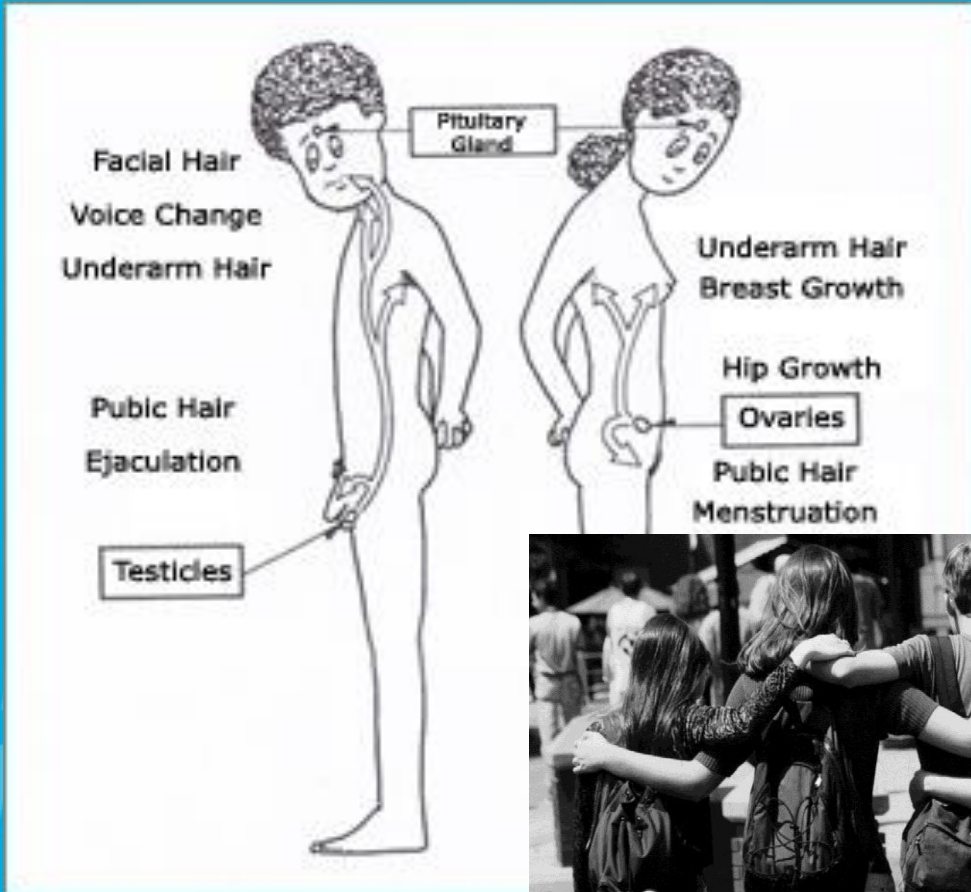


## In clinic: Involve the child!!

- Actively involve the child in treatment plan!
- Talk with the child

A child with CF is more  
than a patient





- Identity
- Body image
- Friendships
- Sexuality - contraception
- Experimenting (smoking, drugs, alcohol)
- Time perspective
- School and future!

## + CF

- Being different - abnormal
- Rebellious - defiant
- Anxiety, depression, sadness
- Pretending
  
- CF : Disclosure or secret ?
- New diagnoses (CFRD...)
  
- **Deterioration?**

**Adherence, self-care and  
management!!!**

- (CF) friends: Facebook, internet, texting etc
- Segregation
- Further involvement in treatment
- First steps to adult care



**Most adolescents  
cope well!**



Ana, Barbara and Maya

# The adult with CF



- Work
- Relationship
- Friendships
- Family
- House etc....
- Trust
- Independence
- Fulfilment in life

## + CF

- Deterioration?
- More symptoms - more treatment
- TIME!!! Lack of time!!
- Adherences – choices and barriers
- Independence <-> dependence
- Transplantation?
- Uncertain future?

- Intimacy, relationship, experimenting
- Love and friendship

## + CF

- Disclosure about CF
- Social limitations
  - First kiss and coughing
  - Sexual relations
  - Friends
  - CF friends: segregation
  - Clubs, sports
  - Work, finances, mortgage
- Family: reproductive and sexual health



- Decision making
- The waiting game

If transplantation is not possible (or not wanted)

- Optimal medical care and support
- Up-to-date information
- Empathy
- Psycho-education

- End of life care
- Palliative care
- Euthanasia?

## TIME < > ALLOW SPACE

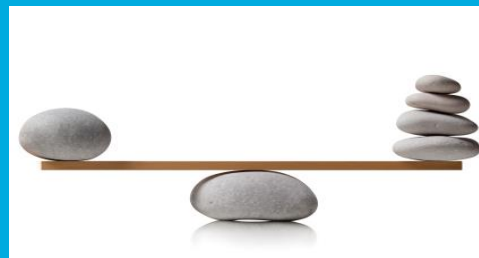
- Compassionate listening
- Acceptance
- Stories – going down memory lane...
- Optimism < > ‘Pretending’
- Wishful thinking and daydreaming

Psycho-education: patient and family (parents, partner, siblings)

Re-assuring: when patient withdraws  
when patient is down and out  
when patient is tired of it all .....

## *The patient and support*

- Personality / temperament / coping
- Parents and parenting
- Siblings
- Home physiotherapist
- Family
- Friends
- Partner
- Education – work
- Culture
- Religion
- Social activities
- .....



## *CF*

- Symptoms
- Treatment and adherence
- Coping
- Anxiety and depression
- Body image
- Eating
- Pain
- Sleeping
- .....

**Holistic Multidisciplinary CF care**

“CF” ≈ Compassion Fatigue

- **Work-related triggers:** caring for chronic illness
  - Sense of unreasonable expectations on the part of some families
  - Seeing kids/young adults unable to have a “normal” life
  - Being the sounding board for too many sad situations

- **Personal triggers:**

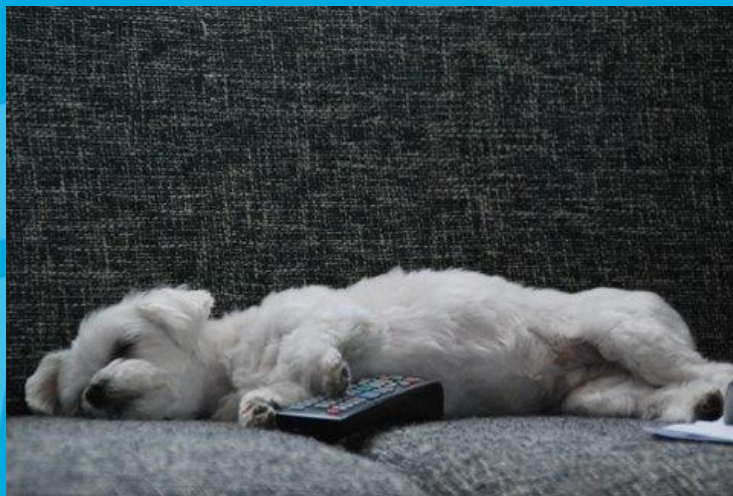
“Overly involved” or “Crossing professional boundaries”

# Recognize signs of BURNOUT and problems (prevent problems from getting worse)



## Don't ignore!

Sleep problems, nightmares, fatigue, feeling down, disillusion in job, frustration, harshness towards team members, decreased commitment, alcohol abuse, feelings of isolation...



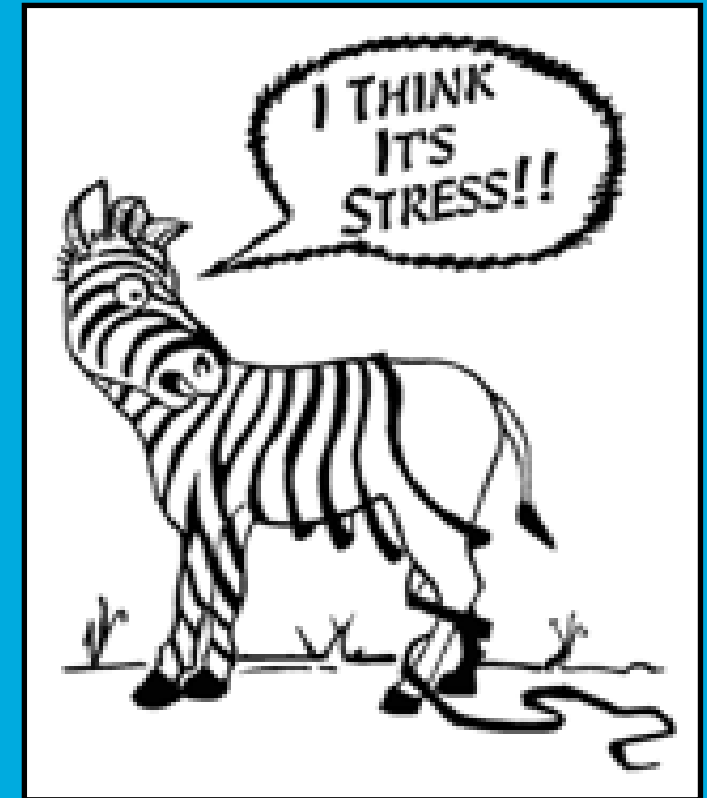
LAUGH at own blunder  
Keep sense of HUMOR

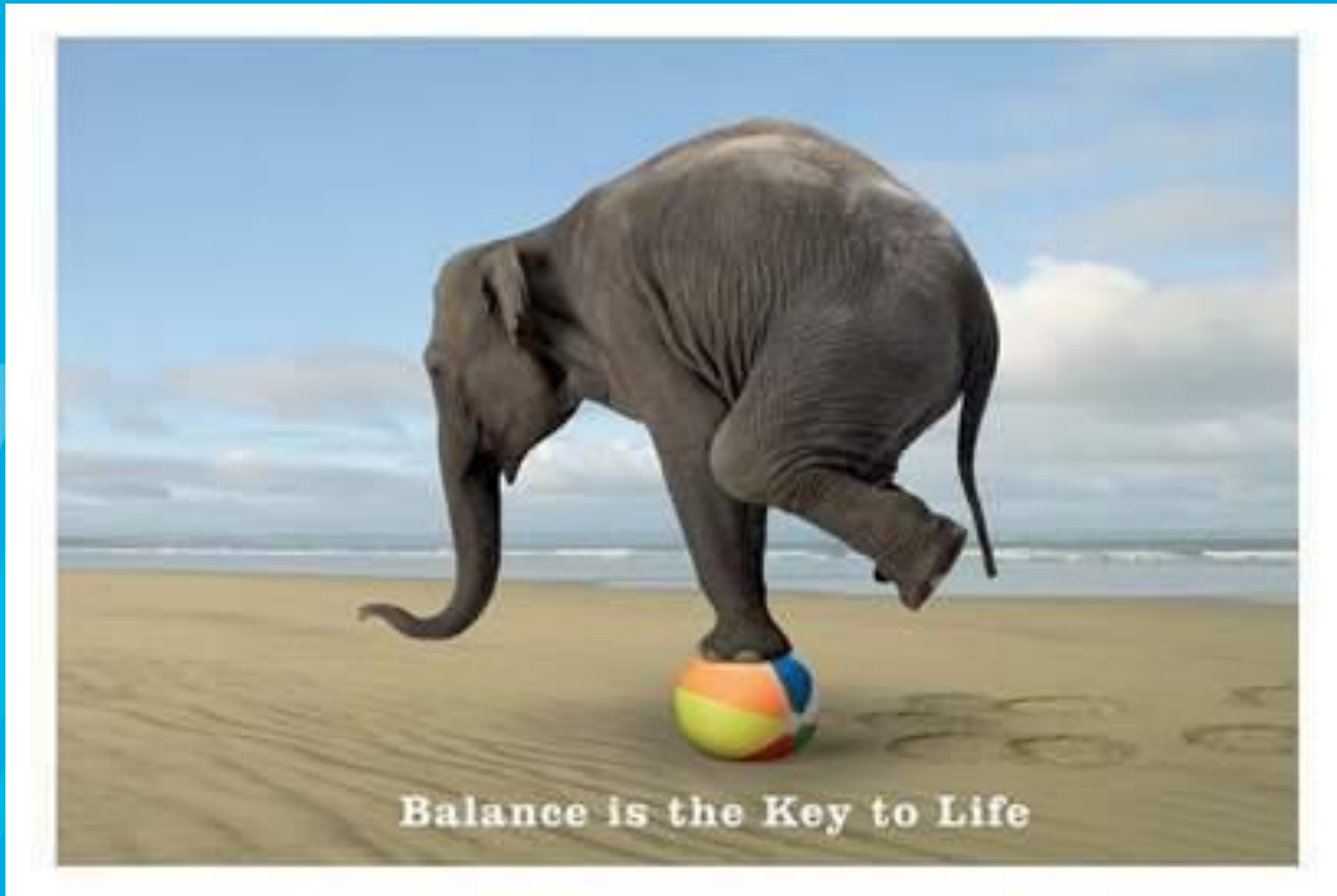
**MAXED OUT  
STRESSED OUT**



Your contribution to the  
**TEAM** is

**small**





Thank you