Bridging the gap in palliative care in the rare disease community
What did I think about palliative care?

Hospice...
Death...
Pain...
End of life care...
WE ARE NOT THERE YET...
What SHOULD it FEEL like?
Palliative care is an **approach**

**improves** the **quality** of life of patients

**and their families** facing the problem associated with life-threatening illness,

through **the prevention and relief** of suffering...
**Approach:** a way of dealing with a situation or problem

**Improves:** makes better/ increases

**Qualities:** standards

**And:** to be taken jointly

**Prevention:** to stop something

**Relief:** the alleviation of pain and discomfort
Palliative care is an approach improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering.

Palliative care is a way of dealing with a situation, that increases / betters the standards of life of patients jointly with their families, through stopping of (suffering) and the alleviation of pain and discomfort.
Bridging the Gap

Hospice...
Death...
Pain...
End of life care...
WE NOT THERE YET...
Barriers to accessing appropriate care...

**Birth**
- Presentation of symptoms

**Symptom Phase**
- Bias based on culture/race/age
- Fear
- Lack of awareness
- Myths / Ignorance

**Diagnostic Phase**
- Testing and Diagnosis (Av 7.2 Years)
- Available testing
- Doctors knowledge & awareness
- Lack of referral systems
- Financial constraints
- Logistic limitations

**Acute Phase**
- Initiation of treatment
- Doctors knowledge & awareness
- Lack of referral systems
- Economic climate
- Funding decisions in state/ private
- Lack of treatment options
- Unregistered medications
- Clinical Trials
- Insufficient Capacity

**Living Beyond**
- Chronic Disease Management Phase
- Pioneering/new area
- Economic
- Fear
- Transport
- Compliance
- Patient Education
- Social

**Death**
- Vague, mimic common issues
- Can be aggressive, or can take years to manifest into something which requires attention
- Symptoms are generally not life threatening = only accumulate into overall condition which then becomes life threatening (if focusing on symptoms alone – doesn’t make strong case)
Diagnostic phase

- 7,2 Years = stagnated care
- Lack of diagnostic facilities – Expensive, lack of capacity/ equipment
- Overseas testing? Confusion on what available in SA
- No confirmed diagnosis – no ICD code – no funding
- No diagnosis?
- Cost of treatment – funding struggle
- Treatment not available locally
- Clinical trials – strictly regulated
- Limited doctors knowledge on disease
- 95% of RD have no commercial treatment
LIVING BEYOND phase = the dream!

- Increased life expectancy
- Reduced mortality
- No longer “acutely” ill
- Emotional Toll
Emotional Impact

- How long is the race?
- Siblings?
- High Divorce rate
- Financial constraints
- Depression / Anxiety

Kelly du Plessis
22 May at 10:44

People often ask how I keep my sense of humour. Drugs folks - not ashamed to admit it either! So often I hear people whispering for their antidepressant in the pharmacy. It's a shame that there is such a "cloud" over people admitting to anxiety and depression. To be honest - I can't bloody wait to take my tablets at night! Without a doubt they keep me sane, happy, and coping!

Be aware guys! So many of us are secretly battling all sorts of issues because we too terrified of what society may think.

#HappyAndProud #LoveMyDrugs #FunctionalAnxiety #SingingInTheRain
WE MOVING FORWARD!

IS THAT THE PROBLEM?!?!?!?!