

LIVING BEYOND

RARE
DISEASES



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?





The WHO Definition



World Health
Organization

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



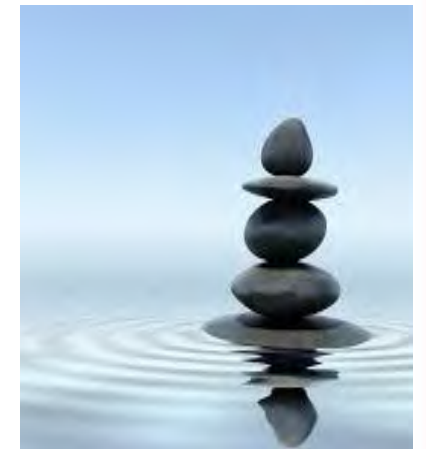
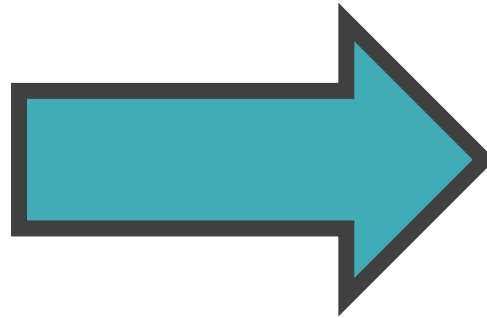
Palliative care is an approach improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering



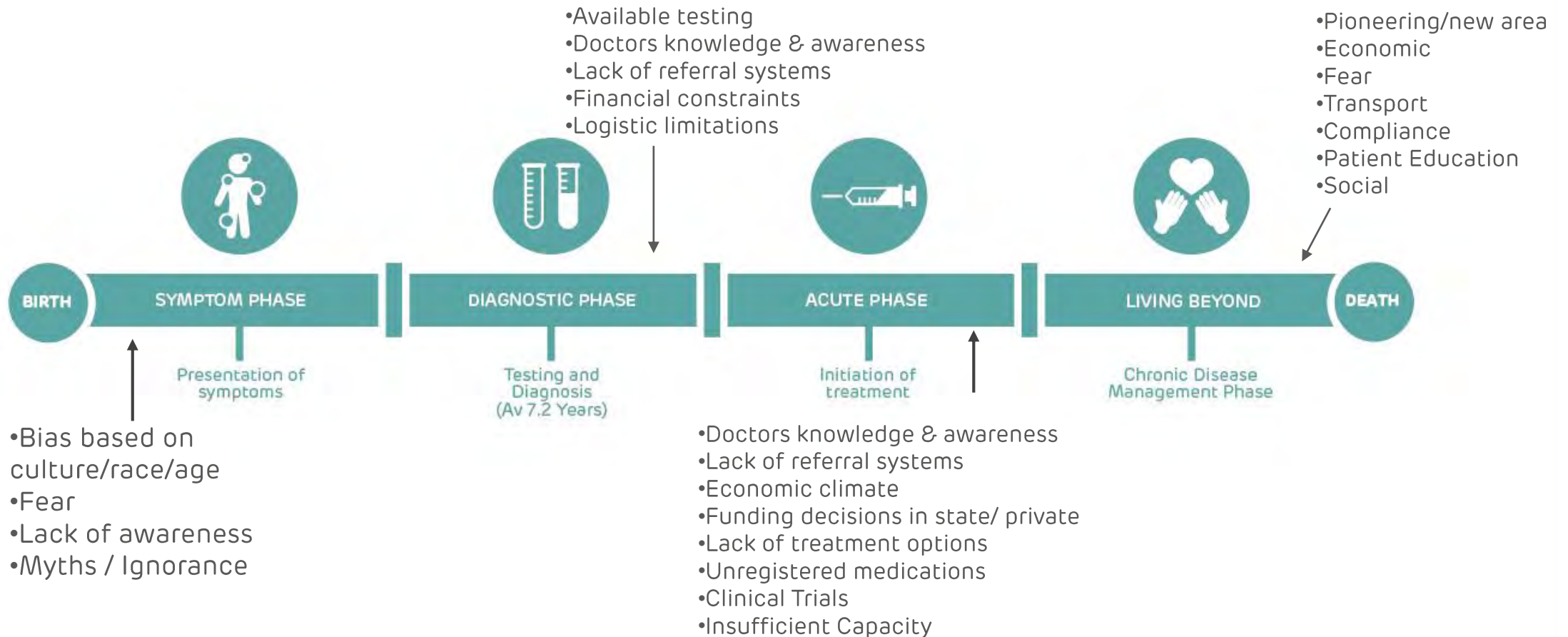
Palliative care is a way of **dealing with a situation**, that **increases / betters** the **standards** of life of patients **jointly** with their families, through **stopping of** (suffering) and the **alleviation of pain and discomfort**

Bridging the Gap

Hospice...
Death...
Pain...
End of life care...
**WE NOT
THERE YET...**



Barriers to accessing appropriate care...



Symptom phase



SYMPTOM PHASE

Presentation of
symptoms

- 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?



Acute phase



ACUTE PHASE

Initiation of
treatment

- 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!



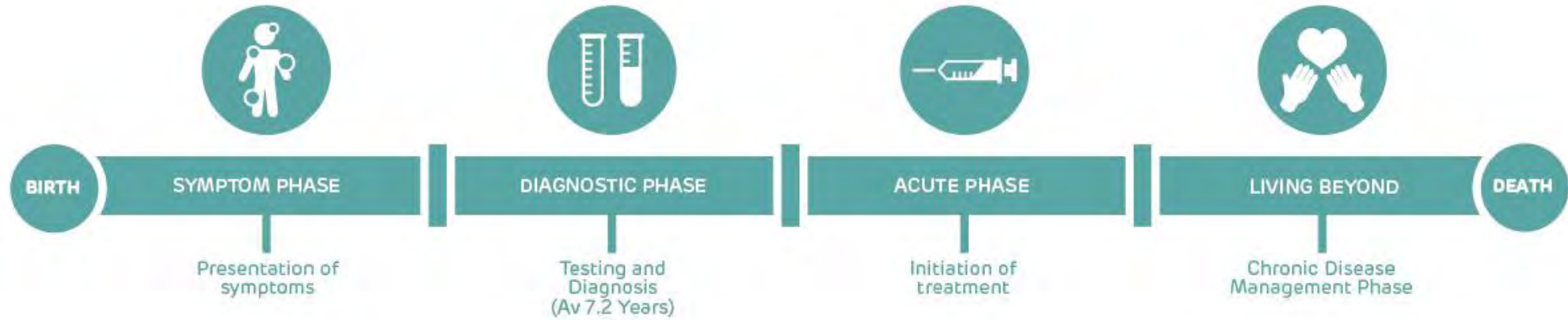
- Increased life expectancy
- Reduced mortality
- No longer “acutely” ill
- Emotional Toll

Emotional Impact

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



WE MOVING FORWARD!



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

