

LIVING BEYOND

RARE
DISEASES



Bridging the gap
RareX 2018





WHAT DO PATIENTS WANT?

But what do patients want?

A doctor that listens to me?!?!?!?

But what do patients want?

- Engagement, interest, ask questions.
- Understand that patients have access to information, respect their feelings on a subject.
- Speak their language – clarity/empathy/compassion
- Look us in the eye
- Be a partner – WE are the ultimate decision makers/ consensus

But what do patients want?

- Take your time – don't rush.
- Do your homework.
- Give options
- Personalize healthcare
- Pass us along

But what do patients want?

- Don't leave us alone with your receptionists...



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...

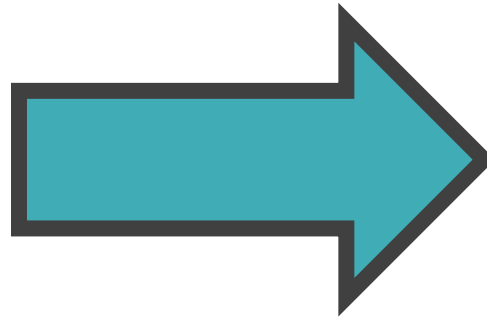
Death...

Pain...

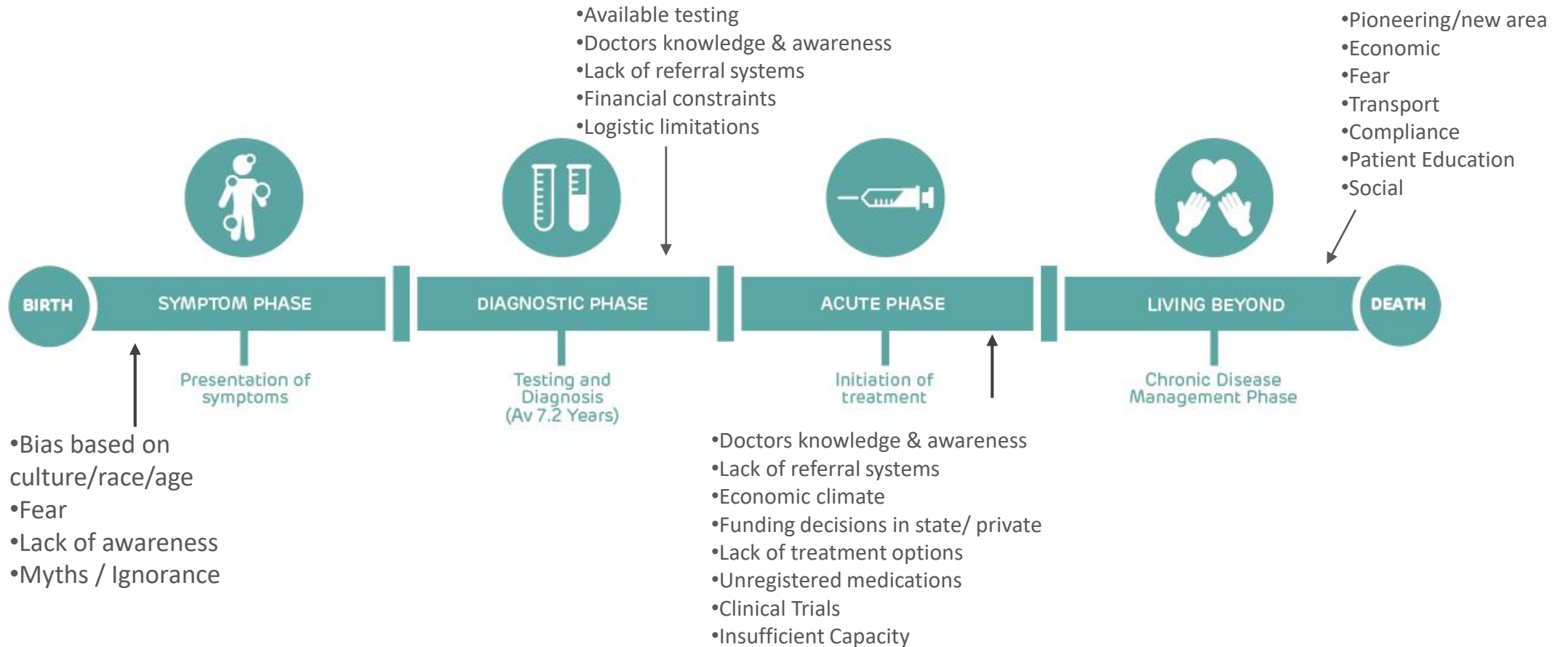
End of life care...

WE NOT THERE

YET...



Barriers to accessing appropriate care...





SYMPTOM PHASE

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

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!

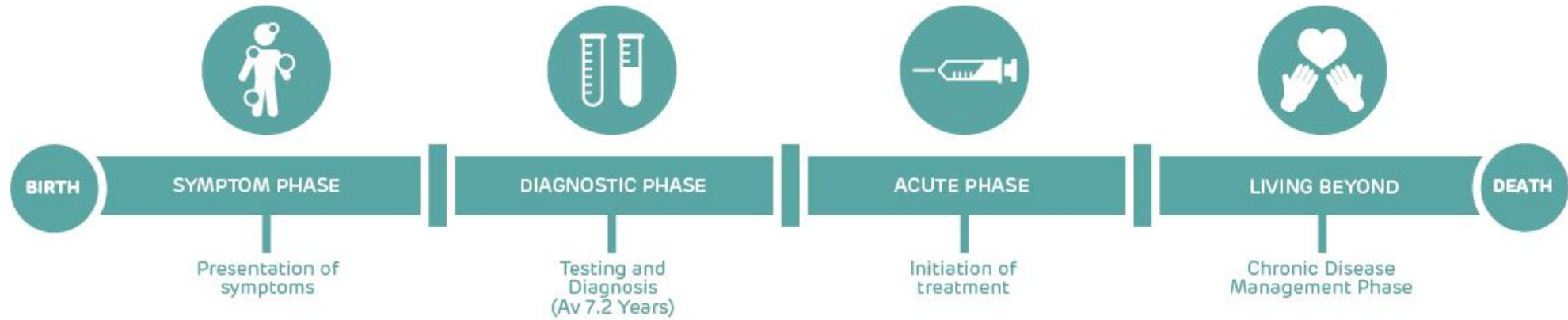


- Increased life expectancy
- Reduced mortality
- No longer “acutely” ill
- Emotional Toll

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



WE MOVING FORWARD!



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



