

# From the Head to the Heart

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**umduwuzi**  
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# Zuhair - Alexanders Disease



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You cannot rush through life when you have a child with a rare disease. Zuhair's diagnosis put my life into slow motion. You learn to have patience beyond measure. Being a parent to a child with a rare disease meant a life full of therapies, questions, appointments. It meant that my life was different and my child was unique. At first I became a doctor, researcher, teacher, biologist in trying to find more information about my child's illness. But I soon realised that the most meaningful use of my time and resources was to focus on my child, finding a team of health care professionals who genuinely care and could ultimately give him the best quality of life. I do think that more research should be done into rare disease, because no life should be determined by how much research has gone into the disease.

# Shana - Neurodegeneration with brain iron accumulation (NBIA)

It would be so helpful if doctors could understand the fear and frustration we experienced going from one doctor to another and not really knowing what is wrong. And then the misdiagnosed cerebral palsy and not understanding Shana's continuous physical deterioration....

# From the Head to the Heart

'Heart Medicine'





## TOP TEN SCIENTIFIC REASONS WHY COMPASSION IS GREAT MEDICINE



1

**COMPASSION CHANGES PATIENTS' PHYSIOLOGY** Non-verbal communication of compassion directly affects patients' autonomic nervous system, breathing, heart rate variation (HRV), reduces stress and increases peacefulness

**COMPASSION REDUCES PAIN** After an empathetic pre-op consultation, patients have better surgical outcomes, better wound healing, use half the dose of morphine and go home earlier (randomized controlled trials)

2



3

**COMPASSION REDUCES READMISSIONS** When patients are given compassionate care in the ER they are 30% less likely to return to the ER for the same problem (randomized controlled trial)

**COMPASSION PROLONGS SURVIVAL** Patients with terminal lung cancer with early access to compassionate palliative care have better quality of life, less depression, fewer interventions, reduced cost of care, and survive on average 30% longer (randomized controlled trial)

4



5

**COMPASSION REDUCES MORTALITY** Having a caring doctor cuts the five-year risk of a heart attack more than aspirin, and reduces overall mortality more than smoking cessation (meta-analysis of randomized controlled trials)

**COMPASSION IMPROVES GLUCOSE CONTROL** Diabetic patients who rate their doctors as 'high empathy' have 42% fewer emergency admissions to hospital

6



7

**COMPASSION IMPROVES TRAUMA OUTCOMES** Surgical trauma patients who rated their doctor 'high empathy' were twenty times more likely to report good outcomes six weeks after discharge

**COMPASSION INCREASES PATIENT ADHERENCE** Patient adherence with treatment is 62% higher when the physician has been trained in empathetic doctor-patient communication (meta-analysis)

8



9

**COMPASSION BOOSTS IMMUNE FUNCTION** Patients with the common cold who receive an empathetic consultation have less severe symptoms, recover earlier and have greater changes in IL-6 and neutrophil count

**COMPASSION REDUCES HEALTH COSTS** Total costs of healthcare in the whole system are 30% lower when the primary care doctor provides 'above median' patient-centered care

10



# Empathy Compassion



# These families need more support



# Reactions

- “I can’t refer to palliative care – the family will think there child is dying or I am abandoning them” Paediatrician
- “We are not giving up hope yet” Paediatrician
- “Am I seeing you because my child is dying?” Rare-parent
- “I google palliative care and it is scary.....” Rare-parent



“We are not ready for you yet Dr Ambler”

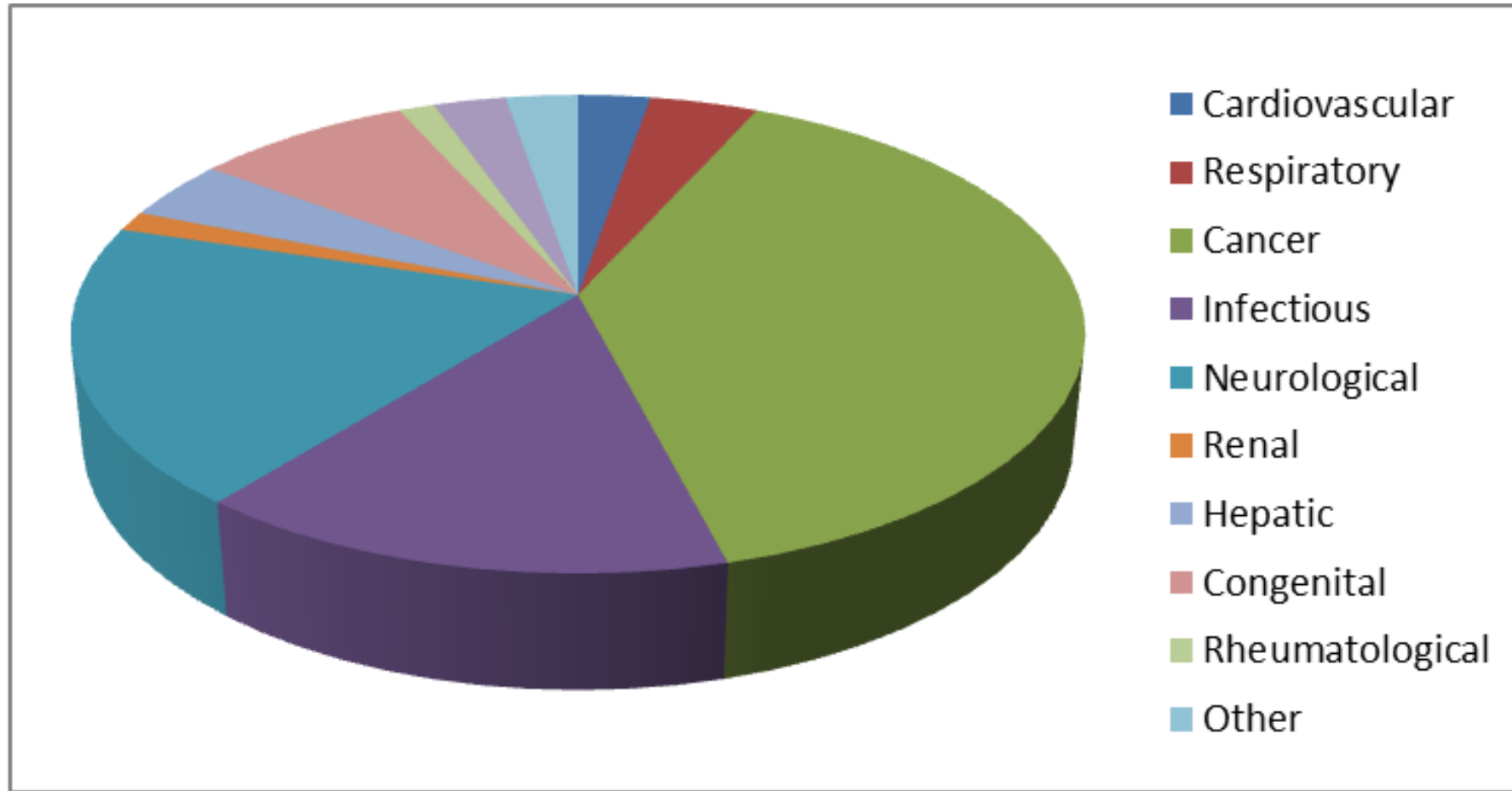


“He’s our new Palliative Specialist!”

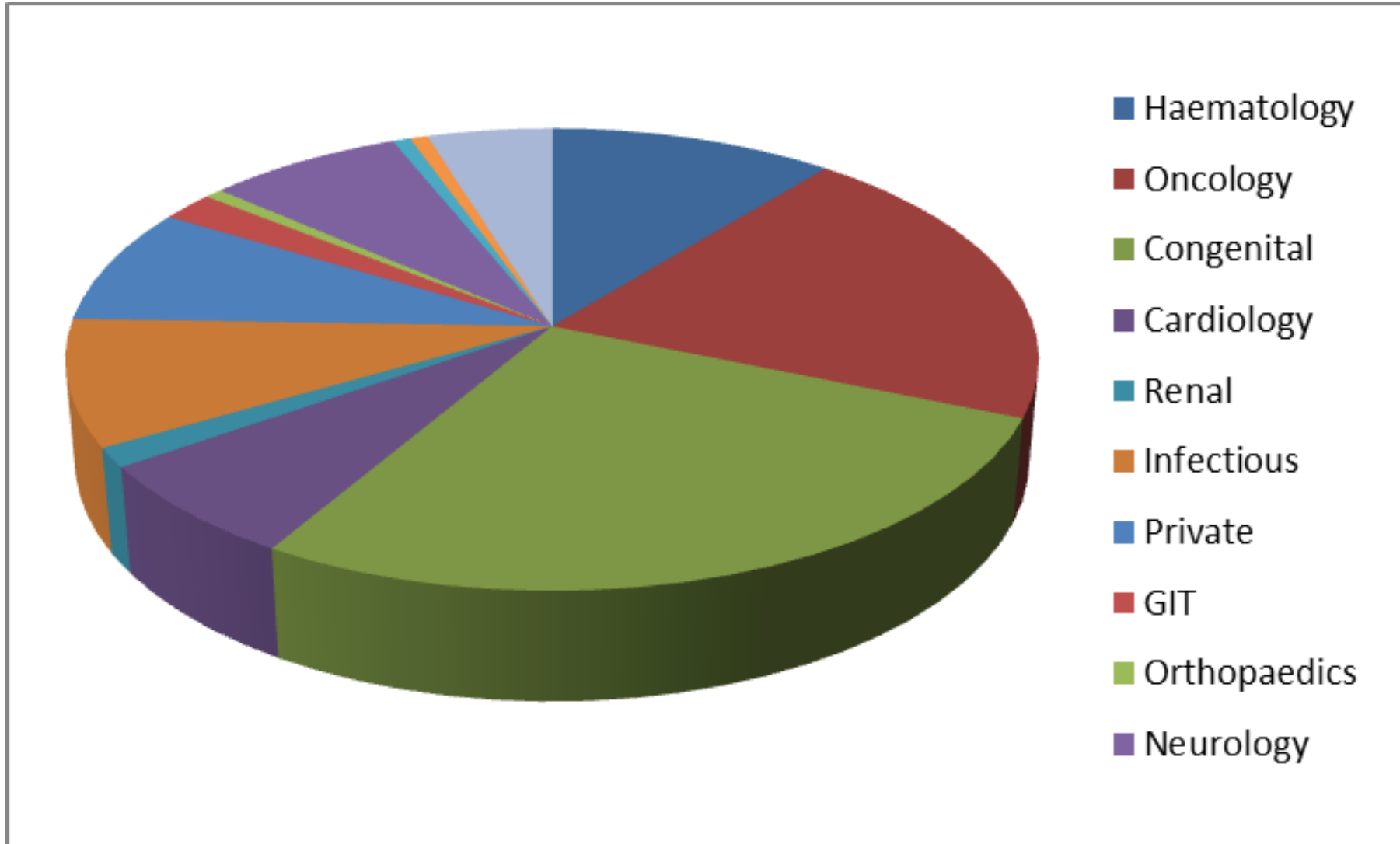
# Shouldn't every rare family have access?

- Challenge understanding
  - Public
  - Health professionals
  - Government
- Advocate
  - Palliative care is good holistic medicine
- Encourage patients and parents to demand and expect it
- Like genetic services – it's a post code lottery
- Time to take a stand

# 2014 – Umduduzi Referrals



# 2017



# National policy framework and strategy for palliative care (NPFSPC)

- In May 2016, Minister Aaron Motsoaledi appointed a National Steering Committee to develop a Policy for Palliative care and address the 9 recommendations of the WHA resolution on palliative care
- The NPFSPC was approved by the National health Council in April 2017
- Now the implementation begins
  - Across levels of healthcare
  - Educational Institutions
  - Professions within health and social care
  - Across clusters – NCD, MCH, HIV, TB

# “Saying we cannot be expected to know about all rare diseases is unacceptable”

But we can

- Communicate (needs elite listening skills!)
- Commiserate
- Journey with us

**We can learn to walk hand in hand with these families.**

**We can provide palliative care**



# #Hatson4CPC - Friday 12 October 2018



Thank you!