



# The role of education in Children's Palliative Care



“Education is not reducible to a mechanical method of instruction. Learning is not a quantity of information to be memorized OR a package of skills to be transferred to learners.....



....Learners need to think critically about subject matter doctrines, the learning process itself and their society.”

Ira Shor



Education in CPC has capacity to do much more than just train professionals to look after children with life-limiting conditions. If properly done by professionals who integrate lived experiences of all into their day to day work, CPC education can promote social justice in health and even be a catalyst to heal the many wounded healers and carers providing health care.

# Social Justice

- The core idea of Social Justice is that all members of a society should have equal benefits and opportunities
- In the work you do for children with palliative care needs, do you promote social justice?





Equitable benefits and support for palliative care children and families, begins with sharing knowledge within our communities

# Education and Learning

- Happens all the time, everywhere
- Formal and Informal
- E-learning
- Research and Publications
  - Evidence Based Practice (EBP)
  - Constantly updated
  - ICPCN
- E hospice



# Education and Learning

- From colleagues
  - Modelling & Impartation
  - Ongoing support & feedback
- From families & children
  - Support (Learning from each other)
  - Telling their stories

# Seize opportunities

- Sow CPC seeds (Sharing information - willing & ready)
- Always be curious to Learn (Building Relationships)
- Then Educate (Disseminate Knowledge)
- Keep things simple!!

“Every job is a self-portrait of the person who does it. Autograph your work with excellence”

- Ted Key



**#HATSON4CPC**

**SHOW YOUR SUPPORT FOR THE  
21 MILLION CHILDREN  
IN THE WORLD NEEDING PALLIATIVE CARE  
BY WEARING A HAT TO WORK OR SCHOOL ON**

# Anya

- Eldest daughter, presented with epilepsy and brain swelling when she was about 7 years old
- Numerous doctors visited
- Exposing her to numerous tests - diagnosed with MELAS syndrome at 13
- Degenerative disease – incurable - affects muscle and brain development

- Amy now 32 years
- Bed bound – 24hr care
- Home care
- Family – adapt outlook on life & lifestyle
- Mom initially quit her job
- Returned after 14years
- Co-ordinator:various societies
- Developed empathy & a drive to help others in need

# Sylvia

- Age 2 – atopic dermatitis, or eczema
- Hospitalised often – smelly bandages
- Pre-school teased for wearing baby-gros
- Flies – get panic attacks
- Open, oozy skin and because it was hypersensitive, I would feel every fly acutely
- Top achiever but always somehow isolated

- “How much of this isolation was just my personality, and how much was because I was, to a certain extent, an outsider, I'll never know. How much of my personality is my illness I'll never know.”
- 16<sup>th</sup> birthday – in tears
- 18years – sacrificed health for the experience and had to bear the consequences – a trip down the Orange River
- Varsity – grades and skin were improving – mental health was not
- Few months later – suicidal
- “I spent so much of my life struggling with my disease that when I became better, I wasn't sure what was left of my identity”
- I never learned independence from my family, I don't think i developed some necessary social skills, and I never experimented with dating (I had my first date and my first kiss about three months ago).

# Sensitising peers and siblings

- educating and involving peers in palliative care is an exceptionally important aspect
- educating the parents of peers
- getting OTs involved is crucial
- helping other children to "walk in the patient's shoes" is very important
- I think that the most important aspect is making "other" acceptable, rather than strange and scary



# Education: Collective Responsibility

- Create awareness
- ICPC Network – “All of us”- one voice - UNITY
- ICPCN banner
- Build relationships



“Whoever teaches, learns in the act of teaching, and whoever learns, teaches in the act of learning.”

- Paulo Freire

# ICPCN Banner

- Spread the word CPC
- Educate others
- Integrate CPC awareness into schools, communities
- #HatsOn4CPC – Get involved

The value of experience lies in what you do with your experiences

# Conclusion

I am hoping that after this conference you are **INSPIRED** to a point where you will identify how you as an individual, in your own country and context, you can be **INNOVATIVE**, rise up against any challenging situations you face, get out of your comfort zone, surprise yourself and challenge the status quo. Go, educate & empower **ALL** on the need for **INTEGRATING** children's palliative care at all levels – not only focusing at health care services, professionals and parents only but disseminate CPC knowledge, information and understanding to **ALL**, including well children and young people.

# Acknowledgements

- All the children, young people and families whose stories have been shared during this conference to inspire all of us – Thank you
- ICPCN and all the staff – for providing continuous Education and Learning for all



- Every shared experience increases the CPC footprint!!!

What is  
your  
Story



Many Thanks!