

# MANAGING CHILDREN'S TOTAL PAIN AND DISTRESSING SYMPTOMS THROUGH WHOLE-PERSON CARE

This workshop moderated by PatchSA and facilitated by Dr Justin Baker and PatchSA members from across South Africa – is a case based exploration of complex pain in a 12 year old boy experiencing phantom limb pain following an amputation for Osteosarcoma.

During the workshop participants will explore all aspects of his total pain including physical, psychological, social, spiritual and cultural. Both pharmacological and non-pharmacological treatments will be addressed by a multi-disciplinary team including palliative care paediatricians, nurses, allied health care practitioners, psycho-social professionals and integrative therapists.

Participants will leave with a comprehensive pain management plan and an approach to help them manage similar challenging cases in practice.



Department of Global Pediatric Medicine  
**ST. JUDE GLOBAL PALLIATIVE CARE**



TIME	ACTIVITY	FACILITATORS	
08h00	Welcome and Introductions	Justin Baker	
08h20	Case Presentation: Jabu's Case Study	Michelle Meiring	
08h25	Theory of Phantom Limb Pain	Justin Baker	
08h40	<b>INSTRUCTIONS FOR BREAKOUT STATIONS:</b>  Each delegate can choose only 3 out of 5 stations  Each station will run 3 times	Pharmacological Management of Phantom limb pain	Tracey Nupen, Yasmin Gogga, Manda Kanka
		Non-Pharmacological management	Tracy Prowse, Tracy Rawlins, Teresa Jennings
		Integrative therapies	Mari Stevens, Fiona McLennan, Angela Rackstraw
		Psychological /emotional pain	Tracey Brand, Crystal Kleinhans, Sue Boucher
		Cultural and Spiritual Pain	Joan Marston, Jan Du Plessis, Busi Nkosi
08h45	Breakout Session 1	Facilitators as above	
09h15	Breakout Session 2		
09h45	Breakout Session 3		
<b>10h15 – 10h45: TEA BREAK</b>			
10h45	Plenary	Each sub-group to present back to plenary Project Google Sheets	Sub-group lead facilitators
12h15	Wrap Up		Justin Baker

# THE LAW, ETHICS AND SHARED DECISION MAKING IN CHILDREN'S PALLIATIVE CARE

**Moderator: PatchSA**

**Facilitators:**

Prof Julia Downing, the CEO of the International Children's Palliative Care Network (ICPCN)

Dr Michelle Meiring: Paedspal, UCT and PatchSA

Dr Lyndal Gibbs, Paedspal and UCT

Lucy Jamieson, The Children's Institute, University of Cape Town

Ethical issues in children's palliative care are challenging enough notwithstanding complexities around shared decision making and guardianship in the South African context. In order to approach these problems, a sound knowledge of legal aspects around guardianship and informed consent is necessary and practitioners need to know how to apply ethical principles to make sound decisions that are made with the patient and the family and not just for them. Paternalism is still rife in settings where caregivers are not empowered or where guardianship is complicated.

This case based workshop facilitated by Prof Downing will provide participants with the necessary background information to manage a complex dilemma. Dr Meiring will address issues around shared decision making, Dr Gibbs will revise basic ethical frameworks including the concept of Ubuntu and Lucy Jamieson will address legal issues around guardianship in South Africa. The audience will then be given the opportunity to participate in a debate.



TIME	ACTIVITY	FACILITATORS
13h30	Welcome and Introduction of topic	Julia Downing
13h50	Case presentation: Caitlin's story	Lyndal Gibbs
14h00	Legal aspects	Lucy Jamieson
14h15	Ethical aspects	Lyndal Gibbs
14h35	Shared decision making	Michelle Meiring
14h40	Debate Instructions	Julia Downing
14h50	Debate preparation: divide into 2 groups	Groups to appoint leader, scribe, debator
<b>15h20 – 15h40 : TEA BREAK</b>		
15h40	DEBATE – GROUP 1 (Helena – Grandmother)	Appointed spokesperson
16h00	DEBATE – GROUP 2 (Skylar- Mother)	Appointed spokesperson
16h20	DISCUSSION	All speakers and facilitators
16h50	WRAP UP	Julia Downing