

Paediatric **E**nd-of-**L**ife national managed
clinical **C**are **N**etwork

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- Can there ever be a situation more devastating for a parent than having to face the end of their child's natural life??
 - ✧ 'the pain is endured by those who are left behind' ... experiences shape the child's legacy, the family's grief - the crushing burden ...

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- The demand
 - 2200 babies, children, adolescents / year become unstable or deteriorate of which 200 will die
 - An additional 200 acute deaths (patients not known to Palliative Care)

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- The problems ...
 - Insidious illness trajectory and care needs
 - Infrequent: changing demand, inequitable service delivery = inequitable choices + inequitable experiences

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- The task of PELiCaN ... to help the family paint the final scene of their autobiography
 - ★ *family-integrated*
 - ★ *what matters to me*
 - ★ *realistic: offering deliverable choices*
- Road shows (exploring wishes and opinions: local possibilities and appetite)
- Stakeholder Launch ... National Conference(s)
- Work streams (data, structural, operational, educational / training, adjunct (psychology, national ethics committee, organ and tissue donation)

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I share a sentiment:

A recently bereaved father said to me ... *'it is just not possible to make a movie that captures the emotions we feel and the admiration we have for you and your team. Not even the greatest movie. It is just not possible'*.

If only his sentiments could be felt by all our families perhaps the horrific burden that is bestowed upon them may be a little less traumatic...

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Thank you

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