

A Big Dream

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Butterfly Children's Hospices set out to pioneer paediatric palliative care in a country with a tragically high number of abandoned sick and dying children

At the start of our journey, the concept of paediatric palliative care was poorly understood, and families had no access to help for a life-limited child



Inspiration

Co-founder inspired as a child watching the film based on Gladys Aylward's mission work with abandoned children in China



Innovation

Showing how good basic palliative care makes a significant difference



Integration

Ensuring the solution fits appropriately within Chinese culture and can be replicated



Understanding the need

- Time spent working in orphanages over 12+ years
- Opportunity discerned to support orphaned children, develop the first dedicated paediatric palliative care (ppc) service

Challenges

- Financial – starting with very little and limited security
- Cultural fears and suspicions
- Personal - founders living as aliens
- No understanding of palliative care
- Staffing – recruiting and training people to work with and love dying children
- Logistics – facilities, equipment and
- Medications - availability and use of morphine for pain relief, paediatric formulations
- No research and statistics available

Method

- Opened a home within a government-run orphanage to care for dying orphans
- With no pre-existing framework, BCH developed a model applicable to the culture and using the limited resources available.
- Worked within the government system to achieve sustainability and gain credibility and support

Goals

- Show what simple palliative care looks like within limited resources
- Introduce and spread the concept of ppc in China
- Reduce the rate of abandonment and keep families together
- Create culturally appropriate and replicable models
- Ensure sustainability

Progress

- Significantly raised awareness of ppc throughout China
- Organised and hosted 3 national conferences in China, one attended by HRH Princess Anne with a 4th national conference organised with Chinese Care for Life Association in Beijing in May 2018
- Translated education and training materials into Chinese
- Funded and produced the first educational video in Chinese
- Delivered training for health care professionals in two major hospitals, assisting them to develop services for families
- Advising government on healthcare policy and ppc standards
- Co-founder/CEO elected an honorary member of the board of the national China Care for Life Association; awarded the MBE by the British Queen; on the board of the ICPCN to represent China
- Two years after opening the first home and using that model, BCH opened a second in another city, now running independently.
- Over 80% of income is generated from within China

The future

Continue to:

- Act as consultants to assist the development of ppc services
 - Develop health policy for ppc with the Chinese government
 - Write the standards for ppc in China
 - Develop other models for hospitals, home and hospice
 - Train Chinese health care professionals
- New developments:**
- Developing projects to help in other orphanages
 - Working with hospitals to develop ppc services and help families
 - Open a family care services centre

Discussion

Although extremely challenging, BCH successfully influenced a sustainable and expanding service in a country with limited access to or knowledge of palliative care.

Learning

Government involvement is the more difficult route, but provides sustainability and spread. Passion, resilience and perseverance are crucial

- May 2018
- 197** children cared for in a Butterfly Home
 - 21** crib capacity and always full
 - 114** children received loving, end of life care
 - 28** children had life-changing surgery
 - 30** children adopted, with 4 more waiting
 - 34** children in other long term care
 - 12** families have received help & advice

It is estimated that 21 million children worldwide are in need of palliative care
4.5 million of those children are in China
Throughout the world the highest proportion of children in need of palliative care die from progressive, non-malignant disease