



When days are short
every hour is precious



Our Charity

BCH was founded by UK couple, Lynda and Alan Gould, with the ambition of alleviating the suffering of life-threatened children and their families in China through the introduction of children's palliative care services.

Working in co-operation with the Chinese government and healthcare organisations, they continue to develop models of loving palliative care and treatment that suits the local situation and values culture.

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers. (IAHPC 2019).

Embracing physical, emotional, social and spiritual elements, palliative care focuses on enhancement of quality of life for the child and support for the whole family and includes the management of distressing symptoms, provision of respite and care from diagnosis through to death and bereavement.



Ten years of short-term volunteering projects in Chinese orphanages gave our charity founders first-hand experience of the circumstances faced by sick and dying children, and the heartache of their families. These children desperately needed loving palliative care to transform their experience from suffering and despair to comfort and joy, however short their lives.

By starting with children who had been orphaned or abandoned, direct care could be provided to meet these children's needs, while demonstrating the benefits of simple palliative care and developing a model that could be rolled out more widely, ultimately reaching families to support them and prevent the need to abandon their child as they had no other hope.

Since 2006, we have provided loving care and treatment for very sick abandoned babies and children at our hospice in Changsha. We are now working in partnership with government, hospitals, social welfare institutions and professional associations, to develop and support holistic models of children's palliative care across China. We have become a beacon in China, advocating, inspiring and training excellence in holistic children's palliative care services.



“Nursing in the Butterfly Home means we continue to treat the children but we also relieve their pain and give the best comfort possible. Our role is to help them live each day to the fullest.”

Chriselle, Butterfly Nurse



We believe that:

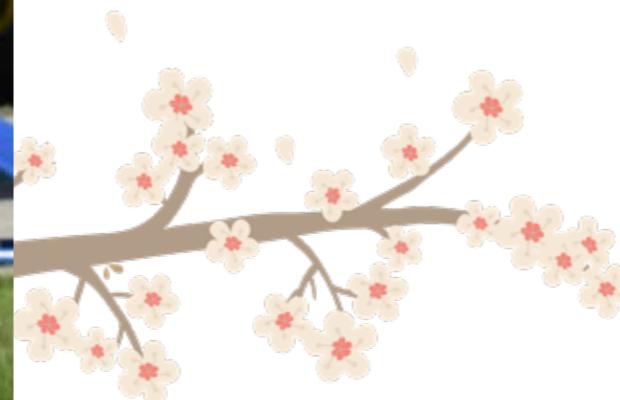
- **Every child's life is valuable**, and should be valued, no matter how short.
- **The voice of the child** and their family underpins every action we take.
- **Dignity in death** should be afforded to every child.
- Every child should be given the opportunity to **achieve their full potential in life**.
- Every opportunity should be taken to **educate and support** families, enabling them to make informed choices for their child.



We work to promote excellence in children's palliative and hospice care in China through leadership, collaboration, advocacy and education.

We do this by supporting the complex physical, emotional and social needs of children and their families. The voice of the child underpins everything we do.

We work in cooperation with the government to establish models of children's palliative and hospice care that are sustainable and scalable to multiple communities. We are committed to the promotion of cultural and policy changes at national level.



21 Children under Butterfly Care



Cared for **209 children**, aged from 1 day to 17 years old



113 children received loving, palliative/end of life care



29 children had life-changing surgery



38 children adopted



32 in other long term care

Statistics refer to children directly cared for in our small capacity Home, but indicate the impact of this model if applied appropriately in larger or multiple settings.



Putting life into children's days in the Butterfly Home

Our staff embrace the ethos that every child is given the opportunity to reach their full potential and to achieve appropriate developmental goals, regardless of their life expectancy or what they can contribute to society. We aim to provide a stable, loving environment for these precious, fragile children; somewhere they can feel loved, supported and safe.

Cooperation between Chinese and Western staff has been essential to develop a suitable model of care. There are teams of dedicated Chinese nannies (ayis) who provide 24 hour loving care. These women are remarkable; feeding, bathing, caring and loving these children like their own.

Our team of Western nurses have been instrumental in setting the groundwork for our model, giving children the best clinical care possible, ensuring their comfort and minimising suffering. We are proud to have recruited and trained a team of Chinese nurses to continue the work, another big step towards fulfilling our goal to embed the model in Chinese culture.

Conor's story



This is Conor. He came to us when he was just over 2 and a half years old. He was very sick due to severe brain damage and suffering multiple uncontrollable seizures.



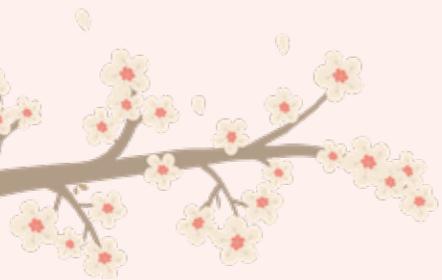
But day by day, week by week Conor's situation stabilised, his seizures were being controlled with the right medication. We began to see a change in him.



A small change, but a hugely important one. He began to become more aware of his surroundings, of his ayis, of other children. He enjoyed sensory therapy and massages. He enjoyed birthday cake on his 6th birthday.



Conor died peacefully and unafraid in the arms of his nurses and ayis a month after his 6th birthday. There were no medical interventions that could save his life and we always knew this day was coming, but we were left grieving for our dear boy. We are thankful for every happy day of his journey with his Butterfly family.



Snowy's story

The day we welcomed a beautiful but very fragile twelve-year-old girl into our home, we were unsure what her future would hold. We gave her the English name, Snowy as her Chinese name translates to Winter Snow.

She was so frightened and sick her ayis spent night and day by her bedside, gently encouraging her and hoping that she might become one of our miracle stories.

Gradually and, in spite of some setbacks, Snowy has become stronger and her recovery has been better than we could have hoped for. Despite all that this girl has been through in her short life, she continues to face each day with bravery, courage and many beautiful smiles and giggles.

The scared, skinny, frightened little girl has vanished. She has been replaced by a happy, sociable girl who loves to be at the centre of activity and has a smile for everybody! She may not love a long life, but she will live knowing security, love and that she is an important member of the Butterfly Family



Listening for the Voice of the Child

It can be difficult for an adult to communicate the pain they are experiencing but it can be impossible for a child to communicate what they are feeling. Whether they are too young, sick or scared, our whole team works together to alleviate suffering as quickly and effectively as possible.

Once a child is no longer in pain, you begin to see the person they really are; what makes them laugh, what comforts them, what brings them joy.

That's why the voice of the child underpins everything that we do and their plan of care is unique to their needs.



It's a great honour for me to come to the Butterfly Home. Children's palliative care is a meaningful career because every child's life is valuable and here I hope to be able to ease their discomfort, bring them love and happiness, and see the children's beautiful smiles every day.

Lily, Butterfly Nurse

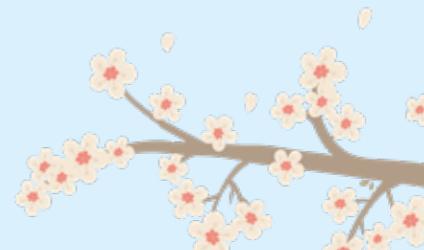


Olivia is a heroine. She was incredibly thin when she arrived; a bundle of fragile sticks looking much younger than her two years. Even experienced volunteers didn't pick her up – not because they didn't want to, but because they were afraid their hands would hurt her.

It turns out that Olivia was stronger than she looked. Her ayis and nurses knew just how to cuddle her, medication helped with her tight limbs, and good nutrition made a world of difference to her. She still cries when her muscles spasm, but it's much less often and she can be comforted.

This is Olivia aged 7 years. There are months when Olivia makes great progress but just as it looks like she might turn a corner, she will be ill and literally fighting for her life again. Nothing comes easy for Olivia, yet she faces each day with a courageous smile and continues to fight. Her crib is also called 'Courage'; who knew it would be such a true reflection of our little fighter?!

We do not what the future will hold for Olivia, but we continue to face each day as she does, with a big smile and hope for a better tomorrow.



Spreading our wings

When the Butterfly Home was opened in 2010, the greatest need was for care of babies and children born with life threatening conditions, most of whom were at end of life in the orphanage.

Provision and access to good health and social care services in China is improving all the time, as are the standards, skills and knowledge of health and social care professionals.

The Butterfly Home has been a great model to demonstrate what children's palliative care (CPC) can look like. However, we have always had an eye on the future to be able to spread the concept and significantly raise awareness of CPC throughout China through such activities as:

- creating a second home in Nanjing, now run under independent management, proving the model;
- translating medical resources and providing the first educational video in Chinese to help grow understanding of CPC;
- holding 4 national conferences to raise awareness, making connections with leaders in the health and social care world and bringing in experts to assist;
- giving lectures at hospitals, universities, conferences and other events throughout China;

- starting a weekly nurse-led clinic for families at Hunan Provincial Children's Hospital;
- opening a 'Butterfly Wing' in the Changsha orphanage to share expertise with orphanage staff and reach children who need special but not end of life care;
- successfully transitioning to an all-Chinese team of nurses in the home to further embed the care within the Chinese system.

Our team has received numerous awards and recognition in and outside of China, including co-founder Lynda Gould given honorary board membership of the national China Care for Life Association and an MBE awarded by Her Majesty Queen Elizabeth II in recognition of services to China.

Lyn Gould speaks at our conference in Beijing. ▶



◀ *HRH Princess Anne visits the Changsha Home in 2017 and delivers the keynote speech at our conference "Spreading the Hope"*

Our Director of Professional Services joins Grand Rounds at the Hunan Provincial Children's Hospital ▶



◀ *Naomi Fu, BCH Director in China, educates and engages supporters and donors in the concept of CPC and the work of Butterfly*

A time of opportunity

The successes of our care in the Butterfly Home and the 4 national conferences hosted by BCH have attracted awards and significant publicity in China.

As a result, BCH has been sought to provide expert advice, training and education for healthcare professionals and hospitals seeking to develop palliative care services for the children and families receiving treatment in their institutions.

We believe BCH is uniquely placed to lead and support the growing movement of children's palliative care in China.

There's more to be done and we will continue to:

- work with partners to develop appropriate service models in hospitals and into the community for families with life limited children;
- strengthen, embed and demonstrate the concept of children's palliative care;
- advocate at government level and input to the development of healthcare policy;
- provide opportunities for delivering customised and appropriate accredited training and education in the field.

Thank you

To every individual and organisation who has...

- **Sponsored** a crib;
- **Donated funds** so generously;
- **Donated** toys, books, clothes, milk and nappies;
- **Given** in response to an appeal so we could buy specially adapted wheelchairs and other equipment;
- **Raised** funds and awareness at events;
- **Spent time** volunteering in the Butterfly Home with the children;
- **Renovated** rooms or worked in our office;
- **Created** the beautiful murals on the walls;
- **Voluntarily run** our social media accounts;
- **Given time and expertise** to help us manage and grow our charity and reach more children.

**You are all part of the Butterfly family.
Let the journey continue.**



Meet Ron!

Our dear Ron. Doctors told us he would probably never walk due to his brain damage. Ron didn't agree. He started walking by his first birthday. He's now been adopted and lives with his wonderful family in America. Ron reminds us every day that miracles can, and do happen.

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