

Care for good days, difficult days, last days and beyond – hospice care for life-limited youngsters

Support and respite for families of life-limited children is rare and diminishing. Hospices fulfil a vital role in providing physical, emotional and spiritual support to parents and siblings. When a child is diagnosed with a life-limiting condition, families often feel isolated and helpless. Naomi House is one of 39 children's hospices in England and Wales that provides one-to-one palliative care that includes respite, terminal and bereavement care and support. It offers a holistic approach to care with an emphasis on enhancing the lives of life-limited children.

Approximately 1,715 children and young people between 0 and 30 years of age died from causes likely to have required palliative care in England in 2004. This amounted to 20% of all deaths from all causes in this age group¹. Behind these stark statistics lies the everyday reality faced by hundreds of families caring for a terminally ill child; families forced to face their worst fear when they discover that their beautiful new baby, so perfect in appearance, has a medical condition that means he or she will never reach adulthood.

Naomi House Children's Hospice (**FIGURE 1**) provides care and support for such parents, including the choice to stay close to their baby after they have passed away by using its special Butterfly suite.

These children may be born through a natural delivery at full term, yet the maternity staff know immediately that something is wrong. Although anyone can refer a family – with their permission – to Naomi House, newborns are usually referred by a paediatric consultant or ward sister in the neonatal unit.

Understandably, parents are often reluctant to set foot over the threshold because they associate hospices with cancer, old age and pain. Visiting Naomi House, which is a purpose-built children's hospice, and experiencing its services for themselves is therefore a crucial part of the admissions process for new families. These visits demonstrate that the philosophy of children's hospices is quite different to that of their adult counterparts, with opportunities for parent respite and an all important break together away from daily care.

Covering central southern England, Hampshire-based Naomi House is celebrating its tenth anniversary this year. In the ten years since it was established it has supported 500 families with life-limited children. Naomi House receives less than 10% of its financing from government and depends entirely on charitable donations for the remaining 90%. The hospice currently provides care and support for 195 life-limited youngsters, from birth to 18 years of age, and their families.

For many new parents the joy of getting to know their newborn is commonly tinged with anxiety about their health and well being. Many will freely admit that they have experienced, even fleetingly, the spine-tingling worry of 'what if' their child becomes

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seriously ill and dies. Usually such morbid thoughts occur when the baby is ill – for example an ear infection easily escalates into meningitis in the minds of most parents. These fears are usually quickly dispelled, however, once the child receives treatment and returns to normal health and vitality.

For mothers and fathers of life-limited children it is often the smallest of signs that trigger the suspicion that their infant is developing differently to others and the resulting fear increases with each doctor's appointment. In other cases, test results during pregnancy have already confirmed a diagnosis. It is a parent's worst fear.

Regardless of how or when parents receive the news, a diagnosis that their child has a life-limiting condition irrevocably changes their lives and those of the wider family and friends. From this day on, notions of normality disappear into a daily struggle to provide care and keep appointments while trying to provide as normal an existence as possible for other children in the family.



FIGURE 1 Naomi House, a purpose-built children's hospice.

The term life-limited is used to describe children with medical conditions that prevent them from living into adulthood, such as irreversible organ failure of heart, liver or kidney; cancer; cystic fibrosis; Batten disease; mucopolysaccharidoses; muscular dystrophy; severe cerebral palsy. Unlike cancer where the disease may be aggressive and the treatment likewise, life-limiting conditions may affect a child for up to two decades or more. Facing the consequences of years of life-limiting illness in a child exhausts the physical and emotional resources of parents; the depth of grief and anguish involved in the death of such a young child is unbelievable.

Naomi House is one of 39 children's hospices in England and Wales which aims to provide care, support and advice at physical, emotional and spiritual levels in order to try to help reduce the suffering of life-limited children and their families. It provides palliative care, including respite, end-of-life and bereavement care for siblings and family members and basic community support.

From its inception, one-to-one care and knowledge of the children, and their families, have been the main stays of provision of care. Every child who comes to Naomi House receives high quality care mixed with clinical expertise, a fun experience and emotional support delivered with kindness and compassion. Its pioneering and innovative clinical team leadership structure, commended by the Healthcare Commission, comprises seven teams, each headed up by a leader with responsibility for a specific area of care such as child and family focus.

Care for good days and difficult days

Palliative care is designed to alleviate the symptoms experienced by someone with an illness or condition that cannot be cured and make them as comfortable as possible. For some children, palliative care is provided after specialised treatment aiming for a cure has proved unsuccessful. For many however, it begins soon after diagnosis of a condition for which there is no cure.

This is where paediatric and adult palliative care differ. Such care is usually offered to adults at the final stage of their illness after treatment has failed. In contrast, most children receiving palliative care have progressive degenerative conditions and the child will become increasingly dependent on their parents, yet support and respite facilities are rare and diminishing.

One-to-one respite care involves a variety of different therapies to stimulate, relax and comfort. Respite care not only helps the children but gives their parents an opportunity for a well-deserved break; a chance for a full night's sleep, an uninterrupted conversation with their spouse, a trip to the cinema or even a holiday – all in the knowledge that their child is being well cared for.

In addition to high care ratios of one staff member to one child, levels of clinical care and professional support, Naomi House also offers youngsters a range of age-specific activities that would not be accessible or available to them elsewhere. With the focus firmly on fun, these enable children of all ages to experience new and exciting activities, enriching their time at the hospice and helping to build their self-esteem and boost their confidence – an important addition to Naomi House's service.

Smaller children are mesmerised by the multi-sensory room, enjoy expressing themselves with art or simply stroking and spending time with Jake, the Children in Hospital Animal Therapy Association (CHATA) dog. The multi-sensory room is one of the most used rooms in the house due to its versatility for all ages.



FIGURE 2 Children find the lights in the multisensory room mesmerising.

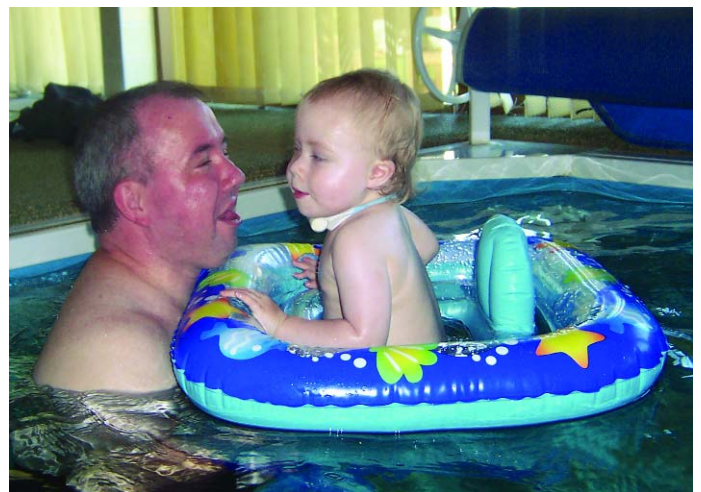


FIGURE 3 The hydrotherapy suite offers opportunities for children and parents to have fun together.

The room is made up of a variety of lights (**FIGURE 2**), a waterbed, music system, ball pool and bubble tubes, all surrounded by soft matting. This room offers both the child and the family a variety of environments. Children often enjoy a soothing relaxing atmosphere but, at a touch of a button, the same equipment can create an interactive environment to stimulate them. We also have a mobile multi-sensory unit for those children who are too poorly to be moved into the multi-sensory room.

Youngsters can also take part in a multitude of sensory experiences overseen by qualified play leaders. These specialists focus solely on the children's needs ensuring play therapy is not only fun but a means of expression, creativity, stimulation and an outlet for communication.

Spending time in the hydrotherapy suite (**FIGURE 3**) is great for children with muscle conditions, stiff joints and limited movement. These children find the water very relaxing and it allows them freedom of movement. The water also alleviates a lot of pressure, which relieves some of the pain the children endure. More mobile children, siblings and parents alike, use the pools as a great source of fun and entertainment, with parents appreciating a late night glass of wine in the heated jacuzzi, which provides some much needed 'me' time.

The children who use Naomi House love to play in the music room. The room is filled with all kinds of instruments including a piano, drums, a wave sound, bells and a karaoke machine just to name a few. Music enables all the children with a variety of



FIGURE 4 The Butterfly bedroom, giving parents time and privacy to say goodbye to their child.

abilities to express themselves and puts a smile on their face. A music therapist also visits twice a week and a professional poet provides regular sessions of rhythm and rhyme to lead youngsters through a voyage of verse.

Care for last days and beyond

The care team at Naomi House offers expert care in the final

stages of a child's life, offering symptom management and support for the family. A 'Butterfly' suite is available for use following death, meaning that the family do not have to leave the staff's care immediately. During this time, the child's body can rest in our Butterfly bedroom (**FIGURE 4**), allowing the family the time to say their goodbyes.

In addition support is offered to help families with difficult but essential practical issues such as registering the death and planning the funeral service. The care team at Naomi House continue to offer support to families after their child has died by keeping in regular contact by telephone and by making home visits.

Once a year a Remembrance Service is held during which families can light a candle in memory of their child. It is also an opportunity to speak with other parents in a similar situation.

A bereaved sibling's day is held annually. This is not only a day packed full of fun activities, but also an opportunity for the children to share their thoughts and feelings with others who have experienced the loss of someone special in their lives guided by qualified, professional members of our bereavement support team.

People often say they could never work in a hospice as they consider it to be all about death. The fact of the matter is that it is about helping people, children and their families achieve the greatest quality of life possible, however short that may be.

References

1. **Commissioning Children's and Young People's Palliative Care Services.** Department of Health, 2005.

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