

# **Needs and Demand Assessment**



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This document highlights a substantial gap between supply and demand of accommodation for a hospice for young adults with life limiting / life threatening illnesses within Essex.

The J's Hospice is seeking to provide services for young adults (aged between 18-40) with life limiting / life threatening illnesses in Essex.

The term 'Palliative Care' has different meanings in children's and adult care; to children and their families it often means respite care, for the children the opportunity for some fun with peers, a place to socialise. It also means symptom control and end of life care similar to adult hospice care.

- **“Palliative care” is not a concept that comes with common understanding or perspectives:** there is an absence of a clearly and consistently applied definition or consideration of “palliative care” – across providers, between children's and adult services, and between health and social care. There is therefore no standard lens or frame through which to view the population in question. Young adults may fall between traditional concepts of palliative care for children and adults.
- **Population data isn't consistently collected from a palliative care perspective:** the lack of common lens means that patient data is not collected in a consistent fashion and may not allow interpretation from a palliative care perspective. There are no explicit or universal registers of patients with palliative care needs.

Population projections for Essex show a flattening of population rise from 2011 to 2020 except in the 25 – 29 age group which rises earlier than the other groups. A review by Gomes and Higginson found that annual numbers of deaths fell by 8% from 1974 to 2003, but were expected to rise by 17% from 2012 to 2030. They also predicted a fall in the number of deaths at home if current trends continue. Given increasing survival of younger people with conditions likely to require palliative care, and predicted increased demand for palliative care for older adults, there is potential for an increased burden on palliative care services to young adults.

*“The number of young people living into adulthood will continue to increase, yet the adult sector and adult physicians may have little experience in paediatric diseases in adult life. There are very few services suitable for young adults (e.g. lack of age appropriate short break facilities that can take young people with very complex health needs and few specialists with a holistic approach to a young person’s care).”*

“Better Care Better Lives,” D.H., 2008

Levels of need are in Chelmsford Borough & Essex:

|                |  |
|----------------|--|
| <b>40</b>      | newly diagnosed young adults with Cancer aged 18 to 25 |
| <b>132</b>     | with Cystic Fibrosis                                   |
| <b>132-164</b> | with severe neurological disability                    |
| <b>46</b>      | with Duchenne Muscular Dystrophy                       |
| <b>7</b>       | with Mucopolysaccharidosis                             |

Cochrane H *et al.*, “Palliative Care Statistics for Children and Young Adults,” London, D.H., 2007.

The annual average of deaths likely to have required palliative care in people aged 15 – 39 in Essex was in a range of 17 – 22 in each PCT and about 100 in Essex.

The Department of Health indicate that the numbers of young adults with life limiting illness is 1.2 to 1.6 per 10,000, and an average of 8,480 deaths from causes likely to have required palliative care in young adults aged 18 to 40.

The current total supply of accommodation in Essex and the region is nil. Adult hospices provide excellent symptom control and end of life care. However they provide less respite than the families are used to in the children’s hospice movement.

The design of the hospice is intended to meet some of the current needs. The J’s hospice will bring together a range of professional skills and services under one roof and offer care and support to young people and their families. Services offered will be:

- Specialised palliative care
- Day care
- Hospice at home
- Specialist respite
- Telephone advice
- Complementary therapies
- Bereavement support
- Employment opportunities
- Independent living

The proposed development takes full cognisance of current government policy, guidance and other up to date best practice advice.

*“Due to advances in medical care, many young people with life limiting conditions are living longer. Many of them can maintain a good quality of life if they and their families are properly supported by services. However they do require increasingly complex levels of support and it is important that services are considered by commissioners in planning end of life services.”*

“End of Life Care Strategy,” D.H., 2008

*“It is acknowledged that there is a wide variation of availability of services for young adults across the country, in particular access to short break care that is appropriate for young people.”*

“Transition Care Pathway,” ACT, 2007

## **The Proposed Development**

The wish is to locate a site within or at the edge of an urban area in a location so that as young people can be near good facilities. This enables the residents to access the town easily and socialise with their peers, relatives and staff. Accessibility to main roads, and public transport is important when you are

disabled and you need to be able to move easily from place to place. There will be times when the young people become unwell and quick access to A&E is essential as these young people can become unwell very quickly and they often require intensive treatment.

The J's Hospice will provide care and support to young adults with life limiting disorders. The Hospice will be registered with the Care Quality Commission and meet their standards. The proposal is for beds for respite care and symptom management including day care. At least one bed will be kept for acute symptom management, emergency and terminal care. Family accommodation will be provided as well as some facilities adjoining the young adult bedrooms.

The J's will offer medical, psychosocial, educational and spiritual care, within an age appropriate environment. The young people will always be involved in making informed decisions and choices regarding their treatment. However, the Hospice will provide an uplifting and supportive environment where young people will be encouraged to live life to the full, however short their lives are. Therefore the hospice will offer complementary therapies, a Jacuzzi, a music and art room, a gym and a bar.

## **Aims**

For all young people to:-

- Gain access to a hospice which has been designed and built to meet their individual and specific needs,
- Receive palliative care provision appropriate to their needs,
- Access services in the Hospice which enhance the quality of their lives,
- Receive innovative and appropriate support through the years leading to end of life,
- Be recognised as a group distinct from children and adults, because their physical, psychological, social and developmental needs are so different,
- Be involved in all aspects of decision making processes.

## **The Policy Context**

The Association for Children and Young Adults (ACT) state that “young adults should be cared for in the environment of their choice. For young adults, a children's hospice is not the most appropriate place and an adult hospice is equally inappropriate.” Young people with cystic fibrosis, Duchenne muscular dystrophy, juvenile Batten's, etc., are surviving beyond 25 but are still dying

young. It must also be recognised that intellectual age may not coincide with chronological age. (Also see previous policy quotes.)

There is a great deal of evidence to endorse the need for the J's Hospice .

- Up to 54% of patients in children's hospices are teenagers.
- There is little experience within the medical and nursing profession of caring for life limited young adults.
- Young adults desire greater independence, which brings particular difficulties as the onset of acute illness often leads to greater dependence.
- The psychological needs of young adults facing their own deaths are not being adequately addressed.

Palliative Care for Young People Aged 13 – 24, ACT, 2007

Over 95% of patients within adult hospices have cancer. Staff may have little experience of caring for such conditions as cerebral palsy, Duchenne muscular dystrophy or metabolic conditions. As less than 1% of patients are under 25, it is impossible for an adult hospice to provide a suitable social environment for young adults.

There is currently only Douglas House in Oxford which is suitable for life limited young adults. This service is not available to young adults in Essex.

Increased life expectancy is stretching the resources of children's hospices and these are not providing the most appropriate environment for young adults.

The J's will work in partnership with the voluntary and statutory sectors to ensure that services are appropriate to the age and development of young adults.

As Nursing Director for the J's Hospice, I have a vast amount of experience in this field. In 1994 I established a paediatric palliative care homecare service, this was a D.o.H. study. In 2005 I specialised in transition for life limited young adults and contributed to *Better Care: Better Lives* and to the ACT *Transition Pathway*. I am an RGN/RSCN with a certificate in Paediatric Oncology. I have a diploma in Paediatric Palliative Care and am working towards a master's degree in Palliative Care.

## References

The Transition Care Pathway, ACT, 2007.

Better Care: Better Lives, DH, 2008.

Palliative Care Statistics for Young Adults, DH, 2007.

End of Life Care Strategy, DH, 2008.

Palliative Care Services for Young People in England. An Independent Review for the Secretary of State for Health, DH, 2007

## **Appendix. Life Limiting Conditions**

### **As defined by the Association for Children's and Young Adults' Palliative Care**

- 1.** Life threatening conditions for which curative treatment may be feasible but can fail. Palliative care may be necessary during periods of prognostic uncertainty and when treatment fails  
  
e.g. Cancer, irreversible organ failure of heart, liver, kidney
- 2.** Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is still possible  
  
e.g. Cystic Fibrosis
- 3.** Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.  
  
e.g. Batten's disease, Muscular Dystrophy, Mucopolysaccharidosis
- 4.** Irreversible but non-progressive conditions with complex healthcare needs leading to complications and likelihood of premature death  
  
e.g. Severe multiple disabilities including severe Cerebral Palsy.