Teenage Cancer Trust

Developing teenage and young adult cancer services
Our History

Teenage Cancer Trust grew out of the dedication and passion of a group of women who discovered the plight of teenagers with cancer by chance.

They went on to raise funds to build the very first Teenage Cancer Trust unit at the Middlesex Hospital in London in 1990.

Our work is focused on providing the very best services for teenagers and young people with cancer and their families. Our core activity is the development of Teenage Cancer Trust units, however Teenage Cancer Trust also funds these additional services:

- Education for the general public, young people and health professionals
- Funded nurses and youth support co-ordinators
- Funding for research
- National policy development & lobbying (IOG)
Why do we provide specialist facilities?

• TCT designs units which provide a ‘normal’ environment for young people with cancer while also meeting their clinical and psycho-social needs.

• This has been proven to increase compliance, well-being and motivation, during a time which can be very upsetting and stressful.

• The psychological impact of the relationship between patients and expert staff is just as important.

• We ensure good design, which creates stimulating and positive surroundings.

• Foundation and catalyst for a dedicated TYA service.
What Types of Cancer Effect Young People?

• Late presenting childhood cancers (rhabdomyosarcoma - sarcoma)

• Common Adolescent cancer (bone tumours)

• Early presenting Adult Cancer (carcinoma)

• All ages (leukaemia/lymphoma)
**Key Characteristics and Social Behaviours of a Young Person**

- Body image – puberty, sexual awakening
- Peer group focus – emancipation from parents and authority figures, family detachment, narcissistic relationships
- Mood swings - contrariness, temper tantrums, testing boundaries, hormone changes, vulnerable to psychological problems
- Functional role in life – career, relationships, lifestyle, financial independence, planning for the future
- Increased risk taking, high energy and greater food intake
Young People and Cancer

- Appearance, peer rejection & social isolation
- Reduced cognitive development & learning
- Non-compliance with treatment & depression
- Emancipation from parents and authority impeded
- Education and employment problems
- Financial discrimination
What do Young People with Cancer want?

• Separate facilities from children & adults
• Dedicated areas & services
• Socialising areas & chill-out zones
• Less desire for privacy and single sex accommodation (teenagers)
• Recreational areas - TV’s, ‘Sky’, music, pool table, Xbox, computers, internet access & mobile phones.
• 24 hour access for their families and friends
• 90% want dedicated services & facilities just for them
• To be normal and get on with normal things!
Current Policy – 106

Safe and effective services as locally as possible, not local services as safe as possible.
Developing a TYA service

‘There is no generic blueprint that can be used to plan an adolescent unit. Populations, establish practices and prejudices, national funding structures, local financial restraints, and politics all have a part to play’

Windebank & Morgan 2003
3 Service Models

Model 1
- SINGLE SITE PTC
- TCT Unit
- Paediatrics & Adult 13-25

Model 2
- TWO SITE PTC
- TCT Unit
- Paediatrics -13-17
- &
- Young Adults -17-25

Model 3
- TWO SITE PTC
- TCT Unit
- Paediatrics -13-17
- &
- Young Adults -17-25
- Excluding
- Haematology
Unit Function

Approach 1

- Maintained clinical responsibility
- Holistic and generic services
- Agreement on supportive care
Approach 2

• Dedicated adolescent clinical team
  – Haematologist
  – Oncologist
  – Paediatric & Adult

• Similar to intensive care specialists
TYA Multidisciplinary Team Function

• Adult practice - site of disease
• Paediatric practice - age based
• Separate psychosocial MDT
• Policy - Teenage & Young Adult MDT
**Core TYA Workforce**

- Clinical TYA Lead
- Lead TYA Nurse
- TYA Social Workers
- TYA Activity Coordinators
- MDT Coordinator
- AHP’s- Psychologists, Physio & OT
Supporting Research

• 2009, The Futures Company, a strategic insight and futures consultancy carried out detailed research and in depth interviews with various stakeholders.

• The study found that within Teenage Cancer Trust units, can provide a positive environment through good design, this should be hand in hand with other key elements such as equipment, staff and culture.

• Design itself is an enabler and is inseparable from these other elements core to TCT philosophy.

• The key benefit delivered by this philosophy is the maintenance of ‘normality’ – manifested through the five key benefit platforms:
Control

• The capacity for patients to take control of important aspects of their day to day lives, for example when to get up and go to sleep, what and when to eat, and their immediate environment including control over lighting and levels of privacy.

• Control is all the more important for young people who, just as they are starting to gain it, suddenly have so much control taken away due to a diagnosis of cancer.
Comfort

• Both physical and emotional comfort - appropriate and comfortable furniture and space for patients and their visitors.

• The creation of an atmosphere that is less institutionalised and threatening to both patients and their friends and family so that they all feel more comfortable spending time in hospital.
Stimulation

• The capacity and facilities for patients to be engaged and stimulated through organised activities and equipment, access to outside space and graphics or designs on the walls and ceilings – all of which help to distract from the day-to-day reality of cancer treatment.
Personalisation

- The ability for patients to take ownership of their space and create a sense of home – particularly important for longer term and end of life care.
Connected

- The ability to keep in touch with normal social support networks, such as friends and family and to maintain all aspects of life including education.

- This is facilitated through flexible visiting hours, social spaces to hang out in and free access to laptops.
While colour does not act in itself as a cure, it does affect mood; thus, the right colours can help to create an attitude which is therapeutic in the sense that it inspires confidence and can banish fear.

Good colour design can make the hospital appear less institutional and a more pleasant and stimulating place to be in.

One group that needs a special approach is the adolescent in hospital; it has been difficult to cater for this group as neither adult nor child spaces are entirely appropriate. The younger person has a definite viewpoint on what constitutes an acceptable environment.

_Dalke, H et.al; Lighting and Colour for Hospital Design_

Teenage Cancer Trust consults with young people on their colour and design preferences.
Colour

**Green**
Soothing and relaxing mentally as well as physically
Helps alleviate depression, nervousness and anxiety
Offers a sense of renewal, self-control and harmony
Associated with feeling relaxed

**Yellow**
Mentally stimulating
Stimulates the nervous system
Activates memory
Encourages communication
Associated with feeling bright and happy

**Orange**
Stimulates activity
Stimulates appetite
Encourages socialization
Low levels of feedback suggesting indifference but mostly associated with happiness

**Blue**
Calming and sedate but can be seen as cold and unwelcoming.
Can symbolise sadness and is thought to suppress hunger
Few negative associations, mainly feelings of relaxation and calm felt

**Purple**
Uplifting
Encourages creativity but can be associated with evil and arrogance
No negative associations, mostly associated with relaxation and creativity.

**Red**
Increases enthusiasm
Stimulates energy but can be aggressive
Can be overpowering and be associated with danger
Associated with feelings of passion and anger

Notes in black are design research findings
Notes in red are feedback from young people
Other Design Considerations

- Safety
- Infection control
- Artwork and images
- Furniture
- Nurse requirements
- Parent and visitor needs
Unit Development

• Currently 15 units
• Aiming for 28 by 2013
Psychological and Social Support for TYAs

• It is important young people are cared for by staff who are attuned to their needs and trained in TYA care
• It is important staff understand young people are not passive recipients of their care – they must embrace their challenging and questioning nature
• Peer group support & friendship is also important and can be strengthened by specialist units
• Young people require a sense of belonging - ‘Christie Crew’ and Find Your Sense of Tumour
• Age specific patient information on issues such as fertility and body image are important
• Family Support Networks funded by Teenage Cancer Trust can be accessed by patients and their families and friends during and after treatment
Function Beyond Environment

For Young People
- Teenage Cancer Trust funds Nurses and Youth Support Co-ordinators
- Peer Support – FYSOT, Online Support Network, Royal Albert Hall workshops
- Education in Schools
- Family Support Networks
- Jimmyteens TV

For Healthcare Professionals
- Professional Development
- TYAC
- Multi-Disciplinary Forum
- Research and funding of Professorial Chair
- Increased revenue funding for posts from 2011/12
Simple Steps

• Justify a need
• Develop working group
• Adapt to local circumstances
• Mobilise key stakeholders
• Design Facilities
• Develop service specification & business plan
• Plan staffing
• Develop your unit
Who the service is for