

# Young adults-how to best support this age group

**19th May : Improving patient experience together.**

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# Order of the session

- What makes young adults unique?
- Impact of a brain tumour on the young adult.
- What does good care and support look like for young adults.
- Barriers to delivery of good care.



# What makes young adults unique?



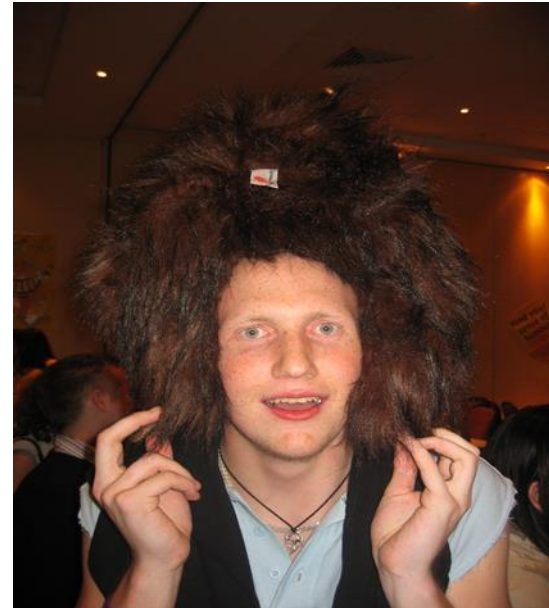
# What makes young adults unique?

- “Youth offers the promise of happiness, but life offers the realities of grief.”  
— Nicholas Sparks, *The Rescue*



# What makes young adults unique?

- “Young people are in a condition like permanent intoxication, because life is sweet and they are growing.”  
Aristotle



# What makes young adults unique?

- The issues of identity were interesting. I still identify myself primarily as a Hodgkin's survivor, rather than a breast cancer patient/survivor, even though I am both. That is because the HD time was so formative, at that stage of life, and made so much of what I am now. The breast cancer at 41 has been difficult and had a big effect on my body and my way of life but not on who I am. The stage of life made it much less disruptive.*



# What makes young adults unique?

- The TYA period of 13-24 yrs old is a time of great turbulence along side great development
- Socially, psychologically and cognitive process.



# Impact of a brain tumour on the young adult

- Brain, other CNS and intracranial tumours form the fourth most commonly diagnosed group of cancers in teenagers and young adults overall, accounting for 14% (7.5% malignant and 6.5% benign, uncertain or unknown) of the total cancers in this age group.
- The numbers of cases are similar in males and females, with a male:female ratio of 11:10.
- This cancer type comprises a range of tumours, including astrocytoma, pituitary adenoma and craniopharyngioma. CRUK 2016





# Impact of a brain tumour on the young adult

- Length of time to diagnosis
  - Not being believed/  
impact on trust
- Treatment is lengthy and complex
- Toxicities of surgery/  
XRT/ chemotherapy
- Long term implications of  
treatment and follow up  
(scans)



# Impact of a brain tumour on a young adult



- Vulnerable life stage
- Developing independence and autonomy
- Developing own identity
- Critical stage in educational and vocational plans
- Executive decision making not fully formed
- Developing sexuality and intimacy
- Intense relationships at this age



# Impact of a brain tumour on a young adult

- Unexpected and rare
- Fear and loss
- Challenges self esteem
- Loss of control
- Increased dependence
- Isolation from peers
- Fertility effects
- Challenges family dynamics
- Cancer overwhelms TYA's coping skills



# What it's like to fight cancer as a teenager

Your hair might fall out

You worry about how your family will cope

You worry about how your friends will treat you

You will miss a lot of school and maybe exams

You have to rely on your family to look after you

You worry about the future

You feel sick and tired a lot of the time

You feel isolated when you're treated in a children's / adult ward

You worry about what your girlfriend or boyfriend will think

You might miss out on nights out/trips with your friends

THE CHRISTIE CANCER TRUST

HELPING YOUNG PEOPLE FIGHT CANCER





# What does good care and support look like for young adults



“ Trying to reassure a 21 year old girl that her boyfriend will still love her even though she has no hair. ”

Caroline,  
Youth Support Coordinator



# What does good care and support look like for young adults



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# What does good care and support look like for young adults





Royal College  
of Nursing



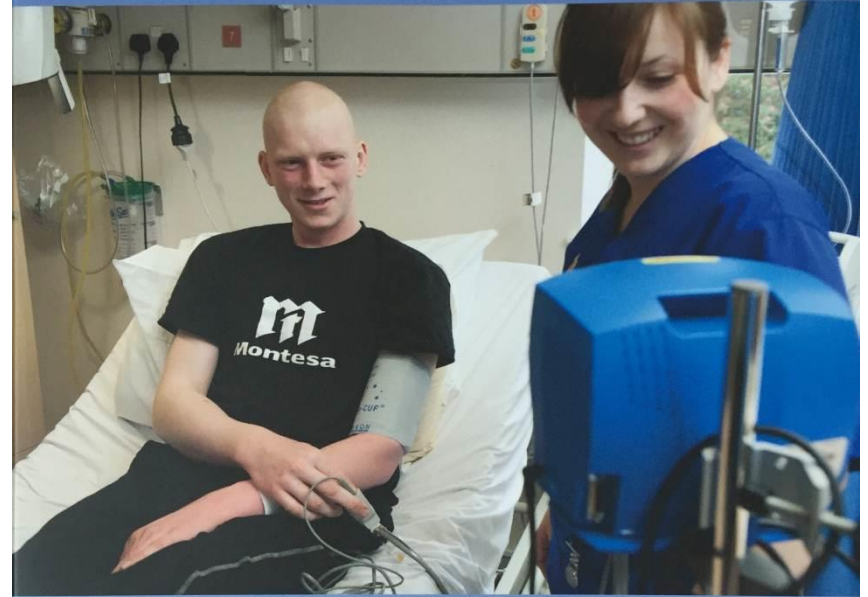
TEENAGE  
CANCER  
TRUST



## COMPETENCIES :

**CARING FOR TEENAGERS AND YOUNG ADULTS  
WITH CANCER: A COMPETENCE AND  
CAREER FRAMEWORK FOR NURSING**

TEENAGE CANCER TRUST ENDORSED BY  
THE ROYAL COLLEGE OF NURSING



**A BLUEPRINT OF CARE FOR  
TEENAGERS AND YOUNG  
ADULTS WITH CANCER**



NHS Foundation Trust

# What does good care and support look like for young adults

- Our Young Ambassadors are an integral part of The Brain Tumour Charity. They help us to raise awareness of brain tumours and are passionate about changing the future for those affected.



# Good Care / Barriers

## TEENAGE CANCER TRUST UNITS



### OPERATIONAL UNITS

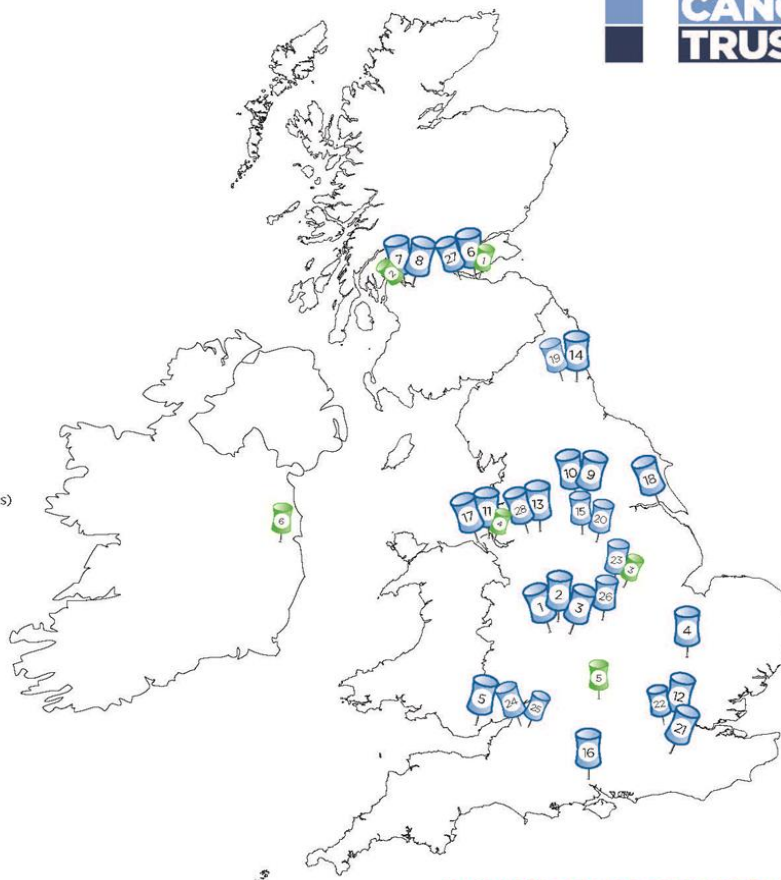
- 1 Birmingham Children's Hospital
- 2 Birmingham, Royal Orthopaedic Hospital
- 3 Birmingham, Queen Elizabeth Hospital
- 4 Cambridge, Addenbrooke's Hospital & Oasis Room
- 5 Cardiff, University Hospital of Wales
- 6 Edinburgh, Royal Hospital for Sick Children
- 7 Glasgow, Royal Hospital for Sick Children, Yorkhill
- 8 Glasgow, Beatson West of Scotland Cancer Centre
- 9 Leeds General Infirmary (Teenage Unit)
- 10 Leeds, St James's University Hospital (Young Adult Unit)
- 11 Liverpool, Alder Hey Children's Hospital
- 12 London, University College Hospital
- 13 Manchester, The Christie Hospital
- 14 Newcastle, The Great North Children's Hospital
- 15 Sheffield, Weston Park Hospital
- 16 Southampton General Hospital
- 17 Wirral, Clatterbridge Centre for Oncology
- 18 Hull, Castle Hill Hospital
- 19 Newcastle, Freeman Hospital
- 20 Sheffield, Royal Hallamshire
- 21 Surrey, The Royal Marsden Hospital
- 22 London, UCLH Cancer Centre
- 23 Nottingham City Hospital
- 24 Bristol, Children's Hospital - adolescent ward refurbishment (11-16 year olds)
- 25 Bristol, Haematology Oncology Centre
- 26 Leicester Royal Infirmary
- 27 Edinburgh, Western General
- 28 Manchester Royal Infirmary



### UNITS IN DEVELOPMENT

- 1 Edinburgh, Royal Hospital for Sick Children (replacement)
- 2 Glasgow, Royal Hospital for Sick Children (replacement)
- 3 Nottingham, Queens Medical Centre
- 4 Alder Hey (replacement)
- 5 Oxford, Churchill Hospital
- 6 Dublin, Our Lady's Hospital

N.B. Some operational units will be replaced in time by another unit sited within a new hospital development



[www.teenagecancertrust.org](http://www.teenagecancertrust.org)



The Christie NHS  
NHS Foundation Trust



# Barriers to delivery of good care

- The 'C' word
- Professionals working together and recognising the speciality.
- Charity and NHS interaction
- Site specialist teams that ignore guidance
- Delivery of choice
- Survivorship and post treatment



- Thanks to .....
- Teenage Cancer Trust and The Christie for funding my role and.....
- The Brain Tumour Charity



# Thank you for your time.

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