



**WE ARE
MACMILLAN.
CANCER SUPPORT**

Developing Teenager and Young Adult Cancer Services at the Royal Surrey County Hospital 'The Challenges and Priorities'

Claire Palles-Clark

Macmillan Clinical Nurse Specialist for Teenagers and
Young Adults with Cancer

c.palles-clark@nhs.net

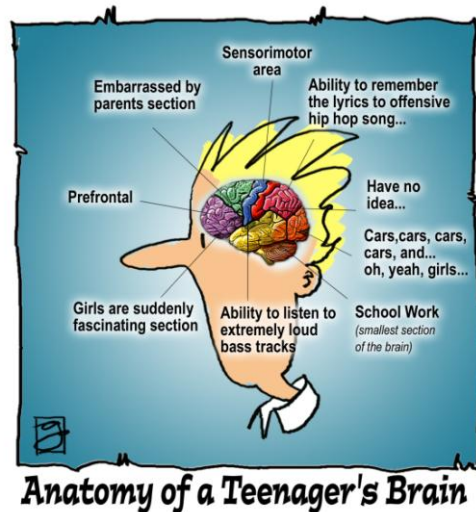
Cancer diagnosis age 16 to 24?

- Less than 2% of all invasive cancer so RARE!
- Still approx 2000 new cases diagnosed yearly.
- 11% of death in this age group
- Most common cause of non accidental death.
- Survival rate not improved at the same rate as children and older adults over last 10 years.



- CRUK 2007

This is Richard.....



Importance of TYA years



- Psychosocially complex
- Body changes – increasing need for privacy
- Gaining of autonomy & independence
- Role of the peer group
- Ability to think about abstract concepts developing eg. mortality
- Make personal decisions about future career, where they will live etc

-

Question for you??

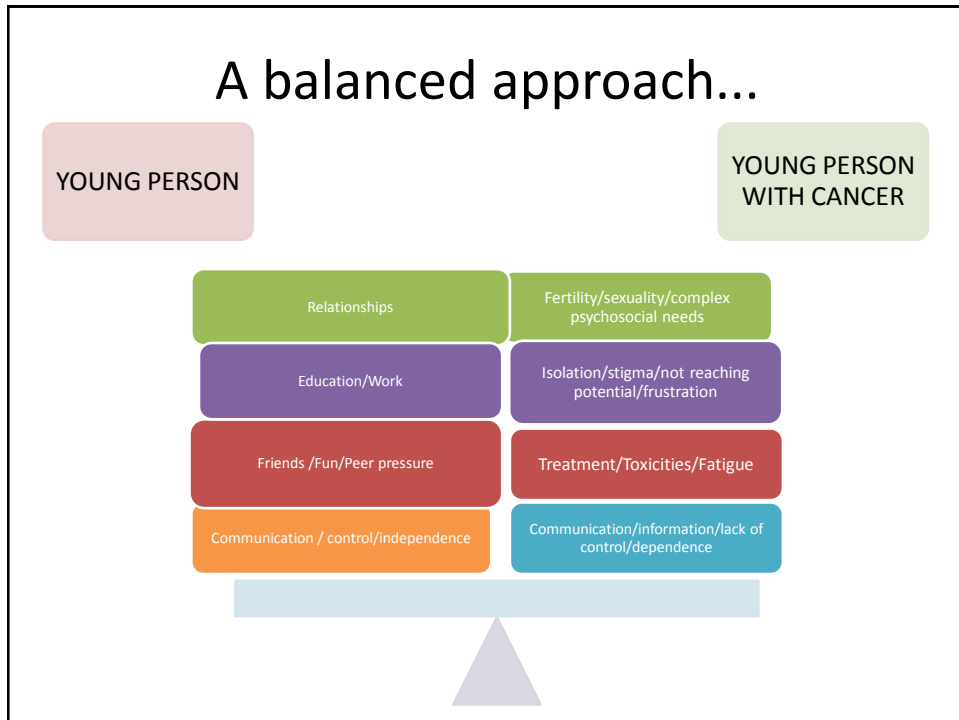
- What are the most common cancers in this age group?




Top 5 most common TYA cancers and their relevant MDTs.

Cancer Research UK (2011) (online)


- Men
 - Testicular (Urology MDT) (27%)
 - Hodgkin's lymphoma (Haematology MDT) (14%)
 - Leukaemia/Non Hodgkin's lymphoma (Haematology MDT) (11%)
 - Bone (Referred to PTC MDT) (9%)
 - Brain (Neuro MDT)
- Women
 - Melanoma (Skin MDT) (17%)
 - Hodgkin's lymphoma (Haematology MDT) (17%)
 - Ovarian cancer (Gynae-oncology MDT) (9%)
 - Thyroid cancer (Head and neck MDT) (9%)
 - Bone (Referred to PTC MDT) (7%)





Governed by policies.....

- Guidance on Improving Outcomes for Children and Young People with Cancer (NICE 2005)
- Cancer Reform Strategy (DH 2007)
- National Cancer Survivorship Initiative (DH 2008)
- Supportive & Palliative Care Guidance (NICE 2004)
- Manual for Cancer Services : Teenage and Young Adult (NCAT DH 2008)



Current model of care



- Principal Treatment Centre(Royal Marsden)
- Designated TYA Hospitals – age appropriate facilities (RSCH)
- Age 16 – 18 : all referrals to PTC
- Age 19 – 24: can have choice of either PTC or designated TYA hospital locally
- TYA MDTs – agree management plan with site specific MDTs
- TYA MDT @ PTC notified of all new diagnoses for Cancer Registry.

Current caseload (Jan 2013 – May 2013)

- 24 patients receiving treatment
- 62 in follow up.
- Types of cancer seen; Breast, Stomach, Parotid, Thyroid, NHL, Testicular, Melanoma, Dermatofibrosarcoma, Ovarian, Cervix, rhabdomyosarcoma, carcinoid, ALL, Hodgkins



Priorities



- Place or setting of TYA cancer care
 - ‘a good place to be if you are having a bad time’
 - ‘all in the same boat’
- Effective Multi-disciplinary team working: site specific & TYA
 - seamless care with collaboration
 - separate but overlapping
- Pathways of care : referral guidelines
- Psychosocial and supportive care : Key workers
- Information about choices - equity
- Age appropriate facilities
- Education
- End of treatment/survivorship or end of life care

Challenges

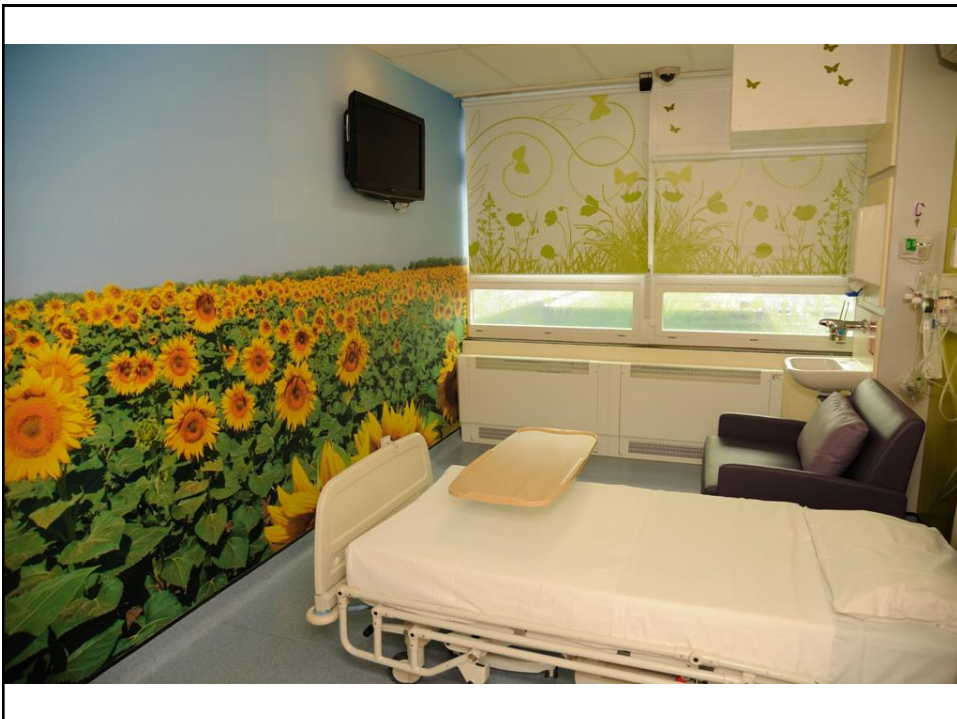


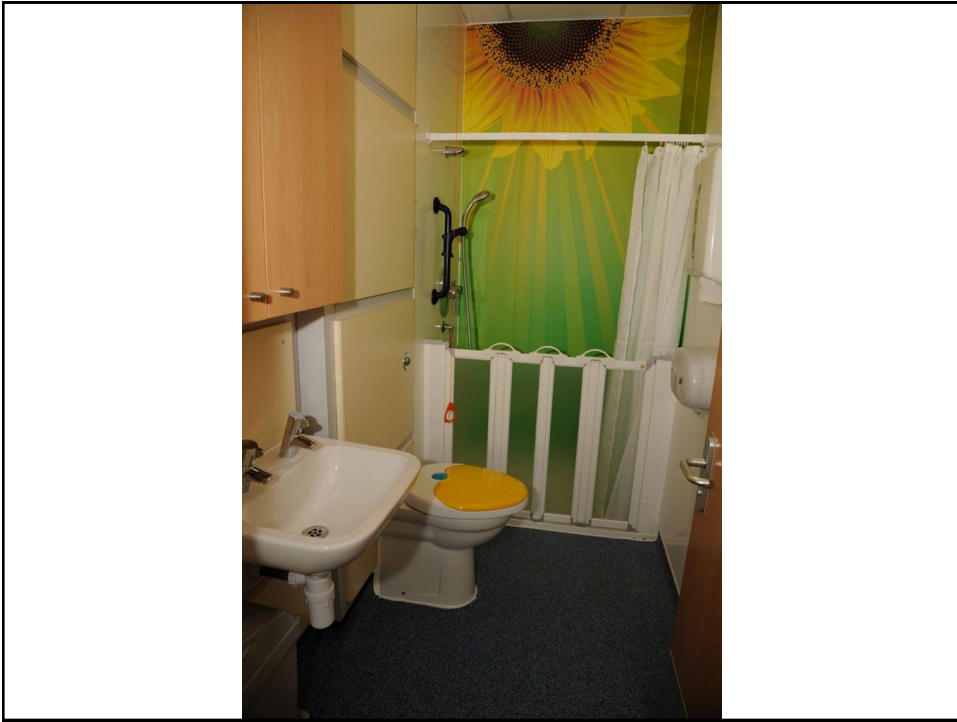
- ‘Persuading doubters’
- Collaboration across SWSH Cancer network
- Referral in from primary care / commissioning
- New models of delivering care
- Evaluation studies of pathways and models of care
- Research – impact the place of TYA cancer care has on patient experience and patient’s reported outcomes.
- Increase access to clinical trials – improve outcomes

Patient stories.....

- http://www.youtube.com/watch?v=YKbzTxBp8so&feature=player_detailpage







TYA CNS role



- Facilitate service transformation locally
- Educate and provide information about infrastructure for;
 - peer support
 - psychosocial support
 - educational and family support
- Involve users
- Educate HCP in primary & secondary care
- Communicate with schools and HEAs

My thoughts.....12 months on!

- Very intense
- Thinking outside the box!
- Outreach TYA service
- Youth worker
- Wide variety of cancers
- Young people often regress
- Complex emotions
- Parents + siblings



WE FUND NURSES
WE CLIMB MOUNTAINS
WE MAKE COFFEE
WE FIGHT INEQUALITY
WE PROVIDE GRANTS
WE SUPPORT FAMILIES
WE CHANGE LIVES

Role of Macmillan Cancer Support in funding CNS posts

CNS role

- Use skills and expertise to provide clinical and emotional support
- Coordinate care services
- Inform and advise patients on clinical + practical issues
- All leading to a positive patient outcome
- Drive for change
- 'People who live with cancer are experts by experience'

INNOVATION
LEADERSHIP
Education
Clinical expertise

Patient experience - Conclusions

- 'a place of their own'
- 'can get on with being teenagers'
- 'chillax areas'
- 'with people who understand'
- 'best treatment possible for best outcome possible'
- 'support with longer term issues'





**WE ARE
MACMILLAN.
CANCER SUPPORT**

Thank you for listening

Any questions?

