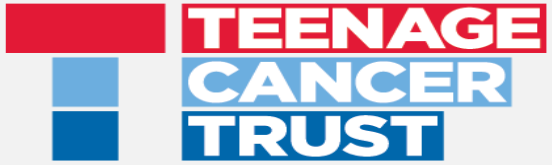




**TEENAGE
CANCER
TRUST**

**Adolescent and Young Adult (AYA) Cancer
Care in England: the history, the
challenges, the successes and the future.**

2nd National AYA Seminar
SPACE4AYA
Amsterdam 5th March 2015



- David Wright
- Teenage Cancer Trust Lead Nurse for Teenagers and Young Adults
- Christie Hospital, Manchester, England
- Adult Haematology 1999-2002
- Teenage and Young Adult Cancer 2002-present day

Overview

- Recognising the need for specialist services.
- How did services evolve in England?
- Where are we now?
- The challenges.
- The successes.
- The future.

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



Stating and recognising the need for specialist care

“Youth offers the promise of happiness, but life offers the realities of grief.”

— **Nicholas Sparks, The Rescue**



- Platt Report 1959
- NAWCH 1990- Setting standards for adolescents in hospital
- RCN 1994- Care of adolescents in hospital
- Youth Matters 1998
- N.I.C.E (I.O.G)2005
- Peer review 2011
- TYA CRG 2013
- NICE Improving Quality 2013/14
- Fern et al 2014

- 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.

Recognising the need for specialist care

- Stage of development children to adult (social interaction, hormones)
- Social issues (peers, education, independence, family, career)
- Psychological needs (invincibility, death, anxiety, positivity)
- Treatment and diagnosis (delays, trials, paediatric/adult interface)
- Survivorship and late effects

How did services evolve in England?

- Pre 1990 no specialist services for AYA's with cancer in UK
- First TCT unit in London (Nov.1990)
- Passionate individuals recognising the needs of young people
- AYA's imprisoned within paediatric or adult services

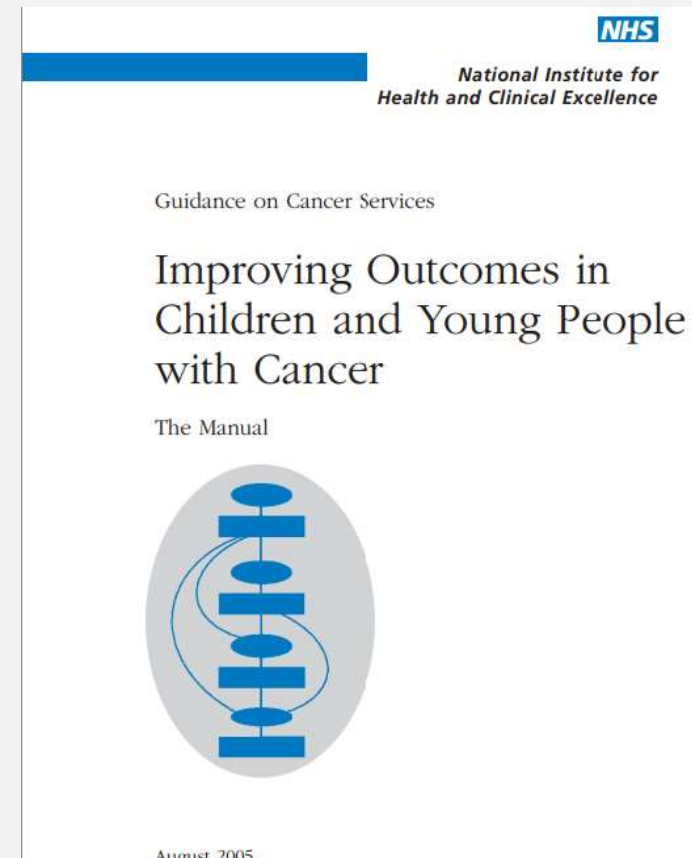


How did services evolve in England?

Passionate Enthusiasts

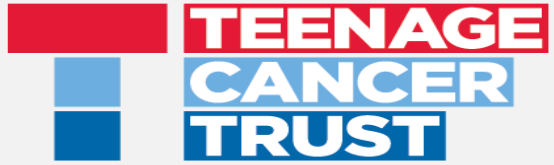
- Out of paediatric philosophy
- Medics and Nurses coming together (TCT MDF)
- International Conference 1994
- First FYSOT 2001
- Continued building of units
- Creation of specialist roles, nurse, YSC, SW
- TYAC 2004 (notification process)
- Harnessing the voice of young people
- Charity lobbying of politicians

Statutory Guidance



Where are we now?

- Principal Treatment Centre's and Designated Hospitals
- Weekly TYA MDT's discussing all new diagnoses that are notified
- Cancer Outcomes and Services Dataset (COSD)
- AYA Peer Review
- TYA CRG



Where are we now?

- 30 specialist units for young people

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 Leicester Royal Infirmary
- 26 Edinburgh, Western General
- 27 Manchester Royal Infirmary

UNITS IN DEVELOPMENT

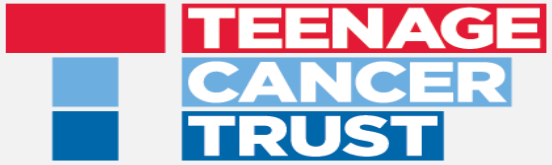
- 1 Bristol, Hospital Oncology Centre - young person's unit (16-24 year olds)
- 2 Edinburgh, Royal Hospital for Sick Children (replacement)
- 3 Glasgow, Royal Hospital for Sick Children (replacement)
- 4 Nottingham, Queens Medical Centre
- 5 Alder Hey (replacement)
- 6 Oxford, Churchill Hospital
- 7 Dublin, Our Lady's Hospital

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



Teenage Cancer Trust Units





Where are we now?

- 30 Specialist units for young people
- Specialist teams
- AYA education programmes for professionals
- Competencies and Blueprint of Care



Where are we now?

- 30 Specialist units for young people
- Specialist teams
- AYA education programmes for professionals
- Competencies for AYA Nurses and Blueprint of Care
- Development of outreach support (TCT and CLIC)
- Education days
- Education and awareness (schools, GP's)

The Challenges

- Professionals working together and recognising the speciality.
- Getting statutory recognition
- Charity and NHS interaction
- Site specialist teams that ignore guidance



The Challenges

- AYA covers all diagnoses and treatments
- Access to trials
- Diagnosis
- Equity across a diverse country
- Delivery of choice
- Survivorship and post treatment
- Ensuring voice of AYA's

The Successes

- Statutory guidance
- All young people have the ability to have treatment in an age appropriate environment.
- All young people across the North West have support from AYA service.
- Charity and NHS interaction

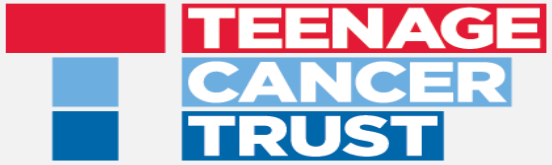


The successes

- TYAC
- International collaboration and development of AYA services (ENTYAC conferences)
- Number of staff supporting AYA's
- Wide range of support activities
- Nurses leading change
- ALL protocols

The Future

- Greater international collaboration
- Aim to have all young people notified to an AYA MDT
- Choice for all
- Increased trial entry for AYA's
- End of treatment and survivorship
- Extended age range
- How we involve our AYA's, learning from the Dutch example
- Hopefully things will become less of a battle 😊



Thanks

- Rosemarie and Winette and the SPACE4AYA organisers
- Sam Smith
- Teenage Cancer Trust
- Christie Hospital
- AYA's and professionals