The challenges of developing Teenage and Young Adult Cancer Services – lessons from experience.

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No Mans’ Land

- But, times have moved on…..
- Work has been done
- Research is being undertaken …and
- now……
- ……the UK is at the forefront of delivering services to this group of patients
- what are the challenges?
Tips from Oscar Wilde:

‘An idea that is not dangerous is unworthy of being called an idea at all.’

‘Experience is the name everyone gives to their mistakes.’
A Good Idea!!

- The development of Teenage Cancer Trust Units – ages 13-24 years
- Around 8 in the UK – with many more in the design and consultation process
- Building the Units is one thing – but developing the Ethos of care is another………

…it’s not only the building that matters – it’s what you do in it that makes the difference…
TYA’s with cancer have specific needs!

• They don’t want to stand out in a crowd
• Don’t want to deal with all their issues
• They want to be educated
• They want to dependent/independent
• To be a brother/sister/partner/son/daughter
• Keep up with their friends
• Social life
• They don’t want to be ill
• And remember…..

They are teenagers first who happen to have cancer
Challenge:

Who should care for and treat TYA’s with cancer?
We believe........

Wherever possible teenagers and young adults in hospital should be provided with their own space, so that they can mix with their own peer group in an age appropriate environment. They should be cared for by experienced professionals who are able to treat, support and guide them.
Who should look after TYA’s?

• Paediatricians?
  Many Units go up to the age of 16 years only…..
  Others up to 24 years………..

• Clinical Trials/Protocols?
  Some up to 18 years – others up to 40 years……………….
Who should look after them?

- **Adults?** Many referrals of all ages and some wards will look after patients as young as 14 years!!!

- **Clinical Trials/Protocols?** Largely adult based, designed for adult tolerance/intensity. Do not have the teenage age group included.
.....actually, these young people are between childhood and adulthood, therefore, they develop diseases seen in both specialist areas....... 

......therefore they need input from BOTH specialist teams........
In an ideal world – the model of the future...

.....would have a mix of both Paediatric and Adult Specialities – we need each other:

An expert TYA Team should be developed, educated and trained to look after this age group – drawn from the two specialities.
The question is this....

Can effective team working be established by drawing together the two disciplines of adult and paediatric oncology – whilst maintaining close working relationships and causing minimal controversy? Oh Yes!!
It was obvious ‘how’ – it was just (at times) excruciatingly painful the journey can be!!
The challenges.....

- Working with MANY teams, opinions, egos, eccentricities, opposition, professional jealousies and ‘ownership’ of the patients.
- Which protocol (i.e. HD, ALL?)
- Why, what if, not enough beds/patients/referrals
- Show me the proof
- Paeds or/vs adults
- Too far to walk!!

CHANGE!!
Managers (some) who could not see beyond budgets, targets and waiting lists……
Challenge: Where’s the Proof?

- Very limited data!
- The UK has focussed largely on developing Units. But, now have professional bodies:
  - TCT
  - TCTMDF
  - TYAC
  - NCRI
  - TCT Chair

A lot coming out of the US – about the survival and accrual into clinical trials
How long would you be prepared to travel for your treatment?

1. Up to a couple of hours' travel - 37%
2. Half a day's travel - 8%
3. A day's travel - 3%
4. Travel needing an overnight stay - 3%
5. Any distance and time - 49%
If you had a choice about the environment you were treated in where would it be?

1. Adult ward
   - 1%

2. Teenage and Young Adult ward
   - 90%

3. Children's ward
   - 9%
Were you treated in a single sex area?

- Yes: 17%
- No: 83%
Which would you prefer?

1. A single sex area
   8%

2. A mixed sex area
   92%
Challenge: The model of Care is different

Paediatric Model:

Very simplified!!
Challenge: The model of Care is different

Adult Model:

- Adult Patient
- Significant others
- Parents
- Friends and family
- Doctors and Treating team

Very simplified!!
TYA relationships can be more complicated!!!
Skills needed!

• The ability to work as a part of a team
• Expertise in the disease process/treatment
• Expertise in the care and understanding of teenagers and young adults
• Communication skills ++
• Non-judgemental
• Not easily shocked
• A sense of humour…..
• Patience…..
• A very thick skin……
• Innovation and creativity, along with an ability to ‘think out of the box!’
And the challenges to us as people.....

• They are wonderful, entertaining, individual young people who are our future!
• They are also inspirational, challenging, heart-warming and frustrating
• And occasionally
       .......heartbreaking.......
So – we need the skills of a team to build them a nest:

‘Not afraid to leave, nor too frightened to return, safe in the knowledge that it’s always there for them.’
Tips?

- Keep the patient at the very centre of developments
- Ask for their opinion and input into services
- Don’t look back, don’t give up, and be very certain of your vision and keep to it!!
- There is no doubt that there will be those professionals who just don’t ‘get it!’ so, include the doubters.
- Learn from mistakes – you will make some!!!!
• Involve the ‘Stakeholders’ at every step

• Especially involve the ‘doubters - those who think it shouldn’t/couldn’t be done!

• Work in partnership with colleagues

• Nurture rather than antagonise new/potential colleagues

• Involve paediatric and adult oncology disciplines - you need each other

• Don’t take things personally

• Don’t give up
• It takes MANY years of nurturing and cherishing diverse practices

• Then VERY slowly neither can remember what they did without the other!!

• Practices in BOTH areas alter to some degree – a cross- pollination has occurred!!

• The others opinion is sought – we have the beginnings of a new team, and we build for the future............