



# Teenage and Young Adult Cancer Care

Liz Purnell

Teenage Cancer Trust Lead Nurse



2006- 2007  
Band 5 staff  
nurse on a  
general  
paediatric  
ward in  
Dewsbury,  
West Yorkshire

2007- 2011  
Band 5 staff  
nurse on a  
TYA Unit in  
Leeds

2011- 2013  
Band 5 staff  
nurse on a  
general  
paediatric  
ward in Bury  
St. Edmunds

2013- 2017  
Band 5 then  
promoted to  
a Band 6 on  
a TYA Unit in  
Cambridge

2017- 2019  
Band 6 on a  
general  
Paediatric  
Ward at  
Ipswich  
Hospital,  
Suffolk

2019-2022  
Haematology  
and Oncology  
Ward  
Manager at  
Sheffield  
Children's  
Hospital

2022- present  
Teenage  
Cancer Trust  
Lead Nurse for  
South  
Yorkshire

## My career and education journey

2006-  
Qualified  
from Hull  
University  
with an  
Advanced  
Diploma in  
Children's  
Nursing

2008-2009  
BSc (Hons)  
Children's  
Nursing  
from Hull  
University

2015  
Mentorship  
at Anglia  
Ruskin  
University

2021  
PG Cert in  
Teenage and  
Young Adult  
Cancer Care  
at Coventry  
University

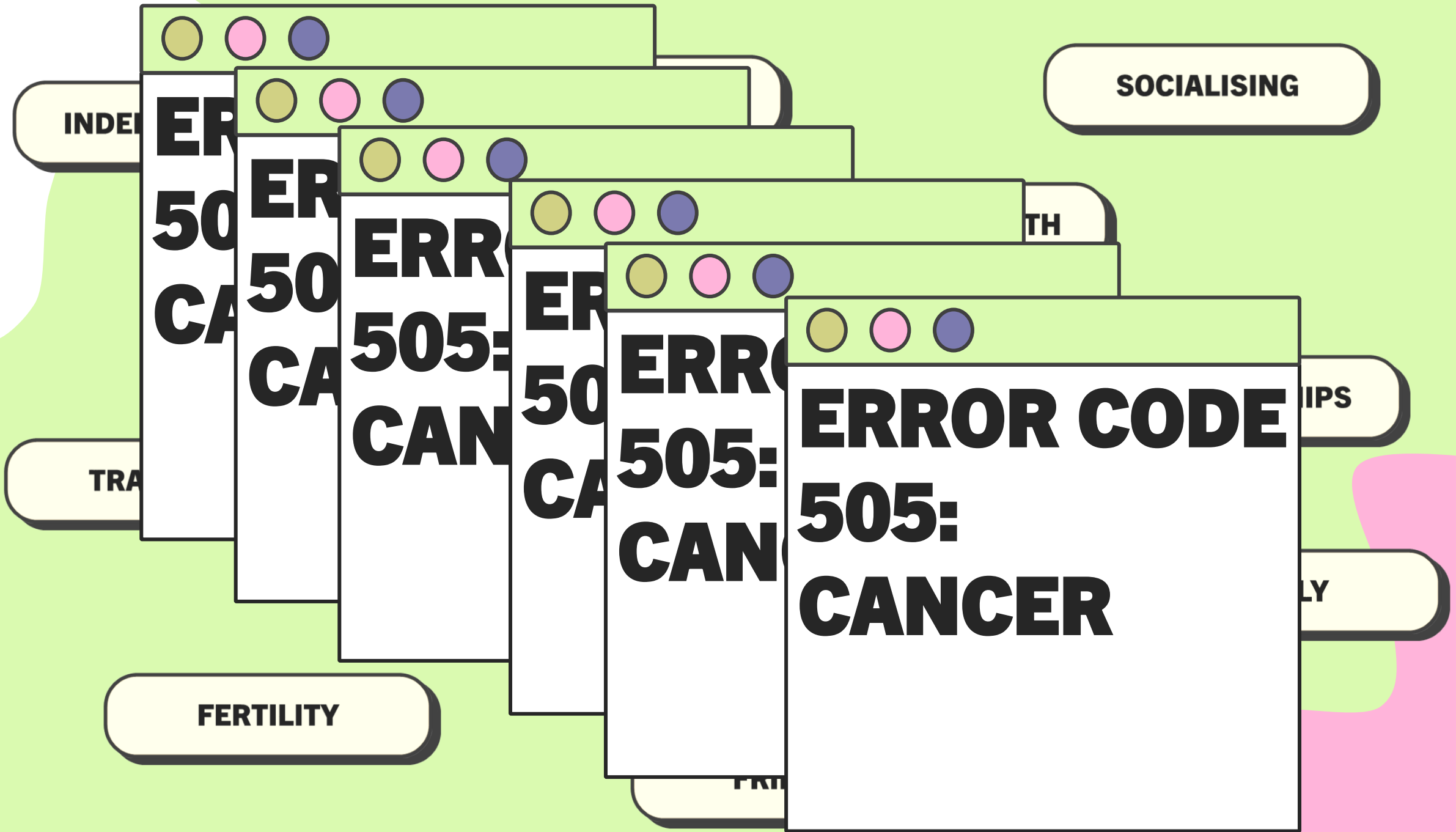
2024- present  
MSC in Child,  
Adolescent and  
Family Mental  
Health at  
Sheffield  
Hallam  
University



## The Adolescent Brain

Teenagers and young adult's brains are in a different stage developmentally from both adults and younger children. The frontal lobe, in charge of reasoning and emotional control, undergoes large changes, and doesn't usually fully develop until late 20's. This results in more risk-taking behaviours, difficulty managing emotions and a push for independence.





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SOCIALISING

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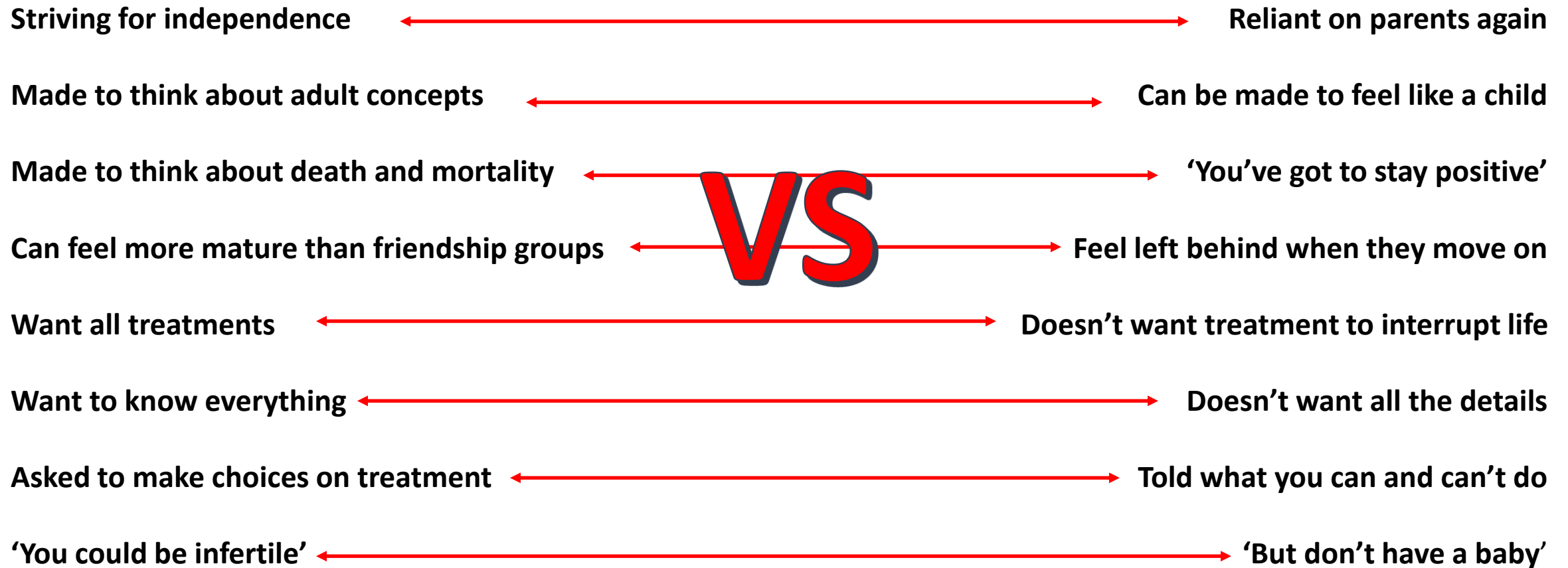
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FERTILITY

FRU



# Cancer creates confusion and opposing feelings





# **TYA CANCER IS RARE**

Cancer in young people is rare, and the type of cancers they get are often rare, or they are anomalies outside of average age ranges.

TYA's have good overall survival rates, however, are often associated with poorer outcomes than that of children or older adults with the same cancer groups.

**WHAT DO TYA SERVICE DO?**



# **WHO ARE WE?**

TYA (Teenage and Young Adult) teams support young people 13-25 and their families with a cancer diagnosis across the UK



- Any young person ages 16-24 must have a referral to the TYA MDT at the Principal Treatment Centre (STH). 16-18 year olds must also be treated at the PTC. Young people aged 19-24 may be given a choice of treatment in either PTC or their Designated Hospital, if their diagnosis doesn't require specialist input from PTC (e.g Sarcoma).
- The TYA MDT hold weekly meetings where new and complex patients are discussed, and anyone working with TYA's are welcome to attend
- Regardless of where a young person chooses to be treated they have full access to the support of the TYA team



# THE TYA MDT

- Lead Clinicians in TYA
- Nurses
- Youth Support Co-Ordinators
- Social Workers
- Psychologists
- MDT Co-Ordinator



# NURSES

- Teenage Cancer Trust Lead Nurse
- Band 7 and 6 CNS
- Provide specialist support and individualised to young people and their families
- Have expert knowledge in TYA cancer care
- Present from diagnosis, through treatment, off treatment, palliative phase and bereavement
- Support young people where they are - inpatient, outpatient, Designated Hospital (DH), hospice and at home/school
- Support staff and provide education
- Act as a link between services/specialties
- Work to improve TYA services and age-appropriate care across the region



# YOUTH SUPPORT CO-ORDINATORS



- Provide emotional and recreational support for TYA cancer patients throughout treatment and for up to 2 years post treatment
- Work with young people on issues such as body image, wig referrals, sexuality, relationships, social isolation, communication with families and peers etc
- Provide opportunities for peer support and social interaction
- Help YP retain a sense of normalcy during treatment
- Support YP into transitioning into life beyond treatment
- Meet young people in environments they are comfortable with e.g home, local café etc



## PEER SUPPORT

Some examples of peer support offered are:

- Meals out
- Look Good Feel Better events
- Coffee dates
- Walking trips
- Fishing trips
- Ellen McArthur sailing trip
- Royal Albert Hall
- Residentials





## **SOCIAL WORKERS**

**YOUNG LIVES  
vs CANCER**

- Funded by Young Lives Vs Cancer
- Provide practical/emotional/financial support to YP and their families
- Support with schools/colleges/careers
- Support young families
- Provide bereavement support
- Help with accessing and applying for grants/benefits
- Helping families adjust to the new situation they find themselves in, and working out how it will affect day-to-day life



# PSYCHOLOGY

- Clinical Psychologists with specialty in TYA cancer
- Work on a referral basis
- Can see patients regardless of where they received treatment
- More young people access service post treatment, but can be at any point from diagnosis
- Also run end of treatment clinic with the YSC, offered to all Young People at EOT



Welcome to the  
***SHEFFIELD***  
Teenage Cancer Trust  
Young Adult Unit


So as you come to the unit in Sheffield



# **Holistic Needs Assessments**

# IAM Portal


IAM INFORMATION

**For Date:**   **Scored By:**  **Cancer Pathway Point:**

**IAM Domain Scores**

<b>Where I am now:</b> <b>2</b> <input type="checkbox"/> Additional notes?	<b>Physical Wellbeing:</b> <b>1</b> <input type="checkbox"/> Additional notes?
<b>Family, friends &amp; relationships:</b> <b>2</b> <input type="checkbox"/> Additional notes?	<b>Education &amp; work:</b> <b>2</b> <input type="checkbox"/> Additional notes?
<b>Housing, transport &amp; finance:</b> <b>1</b> <input type="checkbox"/> Additional notes?	<b>Interests &amp; social life:</b> <b>1</b> <input type="checkbox"/> Additional notes?
<b>Lifestyle:</b> <b>2</b> <input type="checkbox"/> Additional notes?	<b>Sex, sexuality &amp; fertility:</b> <b>2</b> <input type="checkbox"/> Additional notes?
<b>Thoughts &amp; feelings:</b> <b>3</b> <input type="checkbox"/> Additional notes?	<b>Faith, spirituality &amp; culture:</b> <b>1</b> <input type="checkbox"/> Additional notes?

**Additional Information**





# **END OF TREATMENT SUMMARIES**



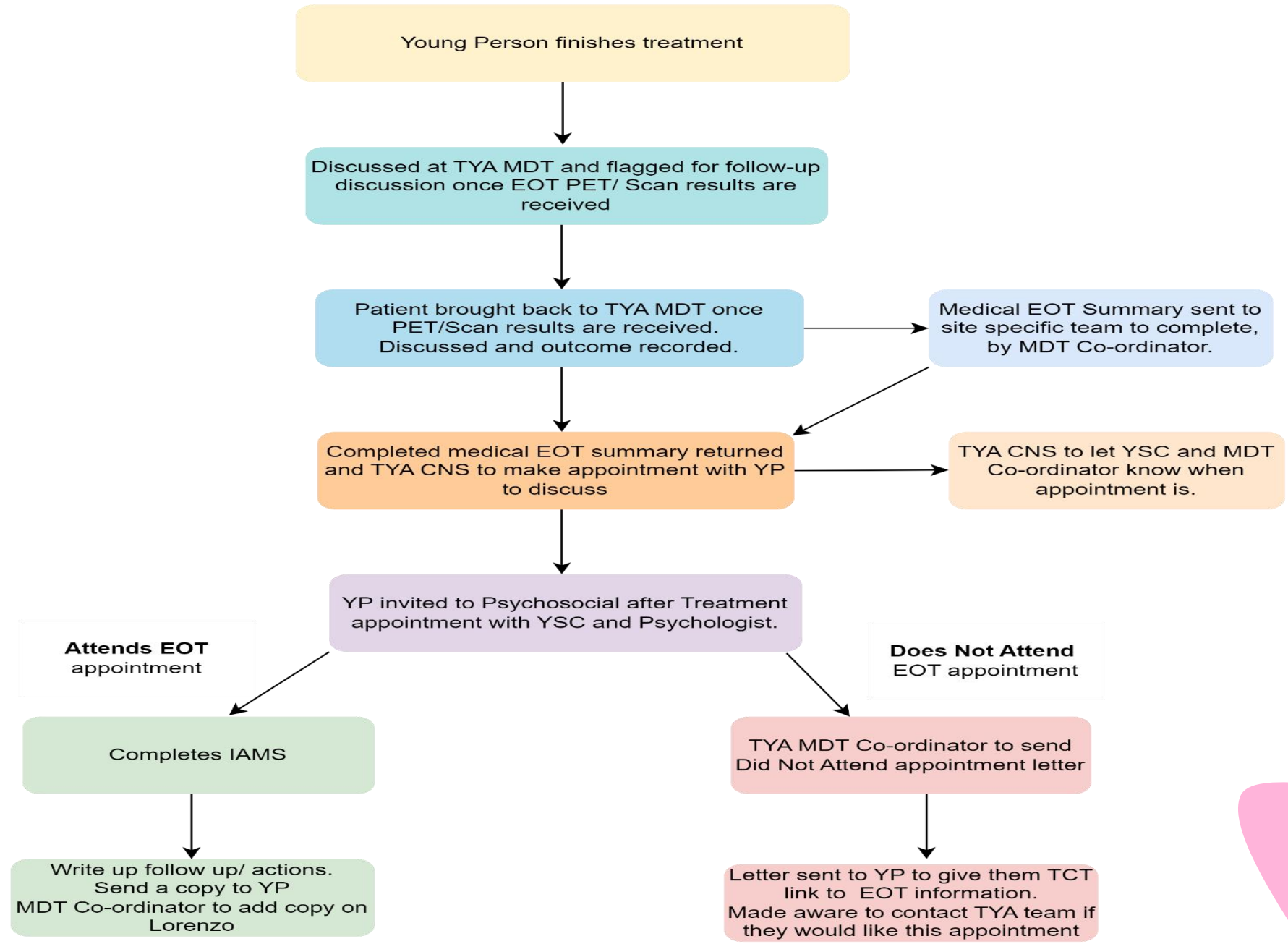
# END OF TREATMENT SUMMARIES

NHS England Service Specification

End of treatment summary: this must be prepared for every patient within 6 months of completing treatment and be provided to the patient / family and GP (and other as appropriate)

[Teenage and Young Adult Cancer Services - End Of Treatment Summaries- Blank - All Documents \(sharepoint.com\)](#)

# TYA End Of Treatment Pathway (Not including Transplant patients)





# **OTHER AREAS OF FOCUS**

- Increasing access to clinical trials
- Transition
- Equitable access to services
- Increasing community-based support
- End of treatment
- Education
- Palliative care
- 16–18-year-olds gaps in service
- IAM Portal



# CHARITIES


**WINSTON'S WISH**  **WINSTONS WISH**

**DRAGONFLY CANCER TRUST**  *Each moment matters*

**TEENAGE CANCER TRUST** 

**ELLA DAWSON FOUNDATION** 

**WESTON PARK CANCER CHARITY** 

**MAKE-A-WISH**  UNITED KINGDOM

 **WILLOW FOUNDATION**

 look good feel better  
FACING CANCER WITH CONFIDENCE **LOOK GOOD FEEL BETTER**

**TREKSTOCK** 

**YOUNG LIVES VS CANCER** 

 **ELLEN MACARTHUR CANCER TRUST**  
rebuilding young people's confidence

**MACMILLAN CANCER SUPPORT** **MACMILLAN**

 **CAVENDISH CANCER CARE**

**LITTLE PRINCESS TRUST** 

# TOP TYA TIPS

**Ask the YP who it is they want involved in conversations – sometimes it's parents, sometimes it's not**

**Try to be flexible around their life –e.g exams, prom, parties**

**Know that YP can and will change their mind. Keep checking in with them!**

**Don't lead with your agenda – focus on what is actually important to young people**

**Think about timings – do they need to be woken up at 9am for meds and breakfast? Can their clinics be later?**

**Listen to them!**

**Acknowledge that on top of their diagnosis, they will still have usual issues facing young people**

**Ask the YP how much info they want, in what level of detail – if they only want the basics, check if there's someone, they want to have more info**

**YP can change topics and have opposing thoughts and opinions – it doesn't mean they haven't understood, it may be how they process**

**Understand YP may express their feelings differently – may not open up, may feel anger, may project feelings onto other people (parents!)**

**Try to avoid telling YP what they 'can't do'(e.g drugs, lifestyle choices, diet) and instead have open and understanding conversations**



**ANY  
QUESTIONS?**