



Psychological impact of Cancer on TYA Strictly TYA 06.09.19

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(Slides acknowledgement Sue Dolby, Dr Laura Baker, Dr Sian Mckenzie, Dr Cara Davis & Dr Claire Semple)





Aims

- Think, talk and reflect on the impact of cancer for TYA
- Why are the developmental changes in the transition to young adulthood important to understand?
- How might cancer and its treatment impact these?
- Are there particular risks to consider?



https://www.teenagecancertr ust.org/sites/default/files/Blu eprintOfCare_2ndEdition.pdf





Does a label of TYA tell us anything about an individual's psychology (think, feel, behave)?



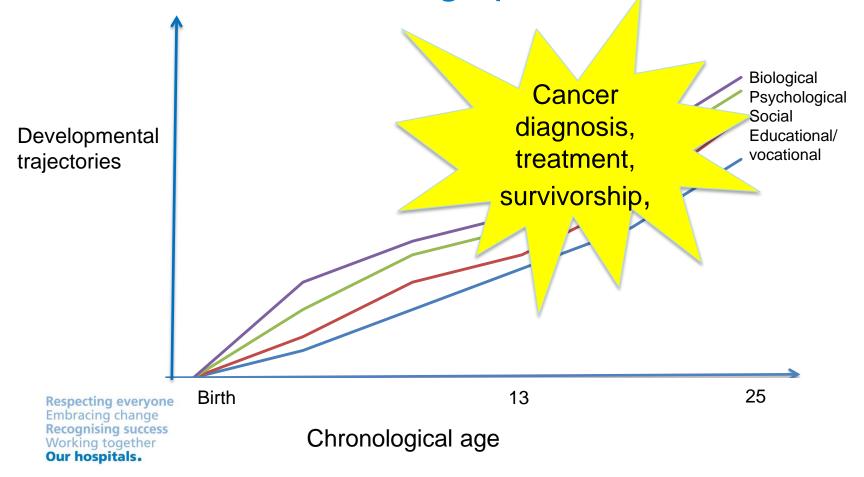


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So is there something special about TYA?

















Bio-psycho-social-vocational development

Cancer pathway









Survivor?

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'Now is not a good time'

(Steven, diagnosed at 18 with Hodgkin's Disease)

'All change.....'

Physical ability, appearance

At risk

Education / vocation

Cognitive & neuro

Peer & intimate relationships



Identity individuation independence

Family relationships

Risk taking behaviours

Beliefs thoughts feelings





Challenges to TYA >>> adulthood

- Life trajectory (education / vocation)
- Developing autonomy
- Shift from parents to peers and partners
- Bodily changes (appearance, sexuality, physical limitations)
- Intimate relationships and sexuality
- Brain development more later
- Mood changes, intensity of feelings
- Changing beliefs about self, others, world
- Self identity and worth (social identity, self-awareness, confidence, autonomy, personal, social and intellectual skills)

New Life >\ Old Life



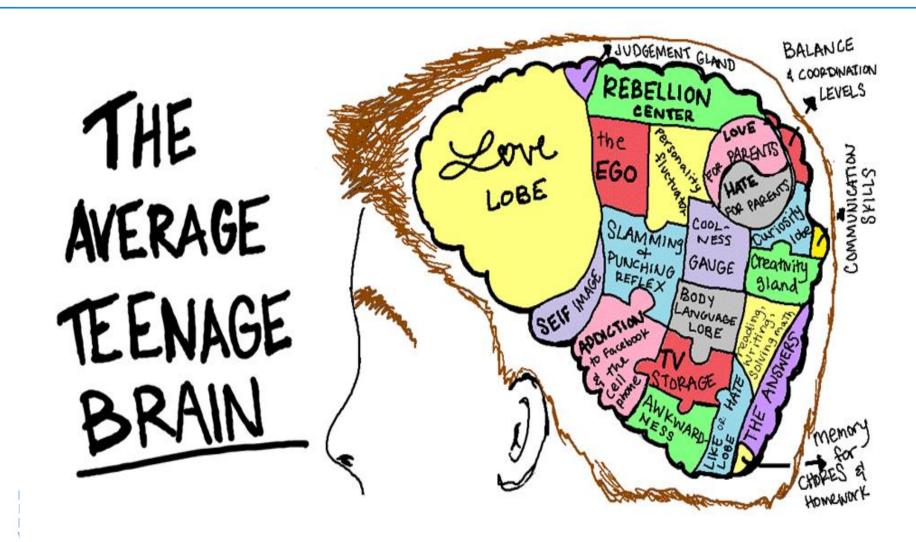




Adjustment or psychosocial adaptation to cancer has been defined as an ongoing process in which the individual patient tries to manage emotional distress, solve specific cancer-related problems, and gain mastery or control over cancer-related life events.



NHS Foundation Trust



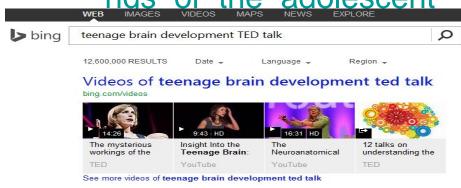


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Brief overview:

https://www.youtube.co m/watch?v=hiduiTq1ei8

https://www.ted.com/talk s/sarah_jayne_blakemor e_the_mysterious_worki ngs_of_the_adolescent

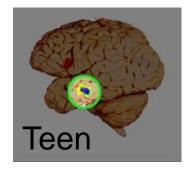


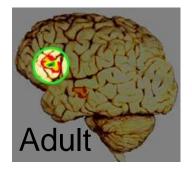
PsychologicalHealth Services



MRI

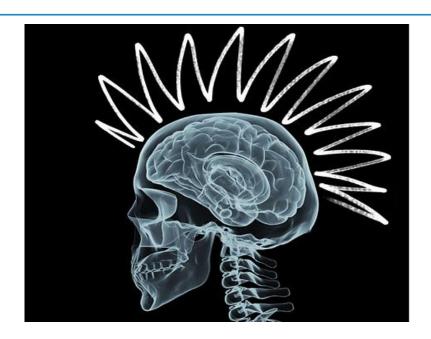






Misread facial expressions

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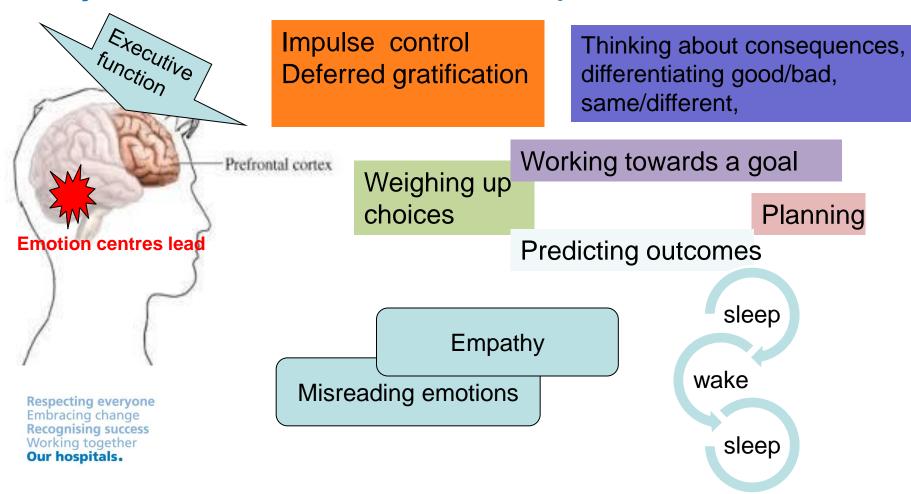
Teenagers release melatonin a couple of hours later in the day than adults, meaning they need lie-ins, Prof Blakemore suggests.

PHOTO: Shutterstock





Why the brain research is important







What impact does this information mean for us in relation to working with teenagers & young adults with cancer?

What are the challenges for the individual – healthcare relationship?





Young person's beliefs, expectations, prorities, thoughts, feelings, behaviour

Differences can lead to conflict

beliefs, expectations, priorities, thoughts, feelings, behaviour

beliefs, expectations, priorities, thoughts, feelings, behaviour









Differences between child and adult services impact:

- Age
- Cultures of care
- Recognition of continued growth & development tolerance of 'immaturity'
- Communication skills
- Patient role/ dynamics of consultation
- Role of parents/carers
- Role of peers
- Role of partners
- Educational / vocational issues
- Confidentiality / consent/capacity/ legislation
- Procedural pain management
- Impact of medical condition
- Multi disciplinary resources
- Involvement of GP

McDonagh JE Growing up Ready for Emerging Adulthood 2007

http://www.erpho.org.uk/Download/Public/15195/1/emerging%20adulthood.pdf

Children's Palliative Care and Adult Palliative Care: Similarities and differences ACT 2007
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Treat us as individuals –
need to know me –
my life – I am more than
my condition

Information,
information,
information, multi
media, in ways I like it
when I need it

Ask us if we want parents with us don't assume ... but also work with them

How to tell other people about my condition

Check how much responsibility I want to/can take then give me skills I need



Don't forget I get /
want to get info and
support from other
places and other
people

Explain how my health condition will impact on being like my friends, jobs, education, finding a partner, having children, being independent, body image, self esteem, confidence, exercising, diet and healthy weight, safe drinking, socialising, etc

Ways to manage my condition and its impact

How to work with my health team

What young people (and their parent carers) tell us they need in transition to adulthood, adult health services and self management





Psychological distress

"an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness, and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in a spiritual crisis."

(Fashoyin-Aje & Martinez 2012)





Does the patient have a problem Or, could the situation be 'the problem'?

- Sustained mortal threat
- Unrelenting change / personal and domestic turmoil
- Interrupted developmental trajectories
- Long, tough medical treatments
- Loss and disability
- Prolonged uncertainty
- Our expectations vs individual resources to adjust

Do we need to understand distress from TYA

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Risk Factors to consider for TYA include

- Genetic predisposition
- Cognitive and learning differences
- Communication differences
- Physical impact cancer and treatment,
- Academic impact
- Low self esteem previous self harm / mental health needs
- Adjustment support
- Peers







Signs of distress and anxiety

- Fears (new/obsessional, extreme, may or may not be related to cancer)
- Scared/anxious
- Seemingly not affected/denial/avoidance
- Talking about suicide/ideation and intent ASK
- Obsessional thoughts,
- Verbal diarrhoea/stopping talking
- Talking just as you are leaving the room (foot in the door)





Signs of distress and anxiety

- Acting out behaviour... I might as well go and...
- Risky behaviour
- Anger
- Targeted aggression
- Sleep disturbances
- Eating problems
- Crying/sadness
- Running away



change?

Personal story

Bío Psycho Social Vocational

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Cancer impact





Unhelpful

- Telling young people what to do
- Confrontation
- Assume 18 = 'adult'
- Using scare tactics with immortals
- Not praising improvements no matter how small
- Not finding out what bio=psycho-social-vocational factors may be influencing engagement / concordance / mood, etc. (It may not be cancer specific)
- Assuming that they can manage it independently







Helpful to

- Do developmentally attuned bio-psycho-social-vocational continuous assessment - individual meaning and impact of cancer and its treatment (hold in mind for IAM presentation later)
- Identify strengths and resilience factors as well as needs and risks
- Negotiate individualised support based on need, readiness to change, preferred strategies for responding with challenges, beliefs about diagnosis, treatment, and ability to influence outcome,
- Use empathic communication that is based on genuine interest in the young person - walk in their developmental shoes
- Be aware of psychological support available and normalise access to it







Applying this in practice

- Jake ,17
- Oldest of 3 children
- Parents separated
- Living in Gloucester, treatment in Bristol (Area 61)
- Osteosarcoma diagnosed after several months of pain in lower right leg picked up after skateboarding fall
- Will need amputation and chemotherapy



- What would we like to know to understand psychological impact for Jake to provide preventative and positive support?
- How would we use this information?





Who am I?

Who was I going to be? Who will I be now?

What I want to do- what will I be able to do?- what do I want to do now?

What I hoped for / expected in my life- what will my life be now? – what do I want my life to be now?

What needs to happen for me to have the future I now hope for?

What changes am I ready to make?



Engaging with young person's individual story





Thank you!

Any questions?

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RISK MATRIX

High Risk: Warning Factors

High Risk Static Factors might include:

Childhood history, eg. sexual abuse

History of suicide attempts

Biological and genetic factors

Suicide in the family

Family history of mental illness

History of violence

Young age at first violent incident

High Risk Dynamic Factors might include:

Misuse of alcohol; prescribed and/or unprescribed drugs

Social situation (unemployment, isolation...)

Others' attitudes to them

Mood disorders

Impulsivity

Self-harm (sometimes)

Changes or problems in relationships (eg, perceived

rejection

Recent clear plans for suicide

Unresponsive / non-compliance to treatment

Destabilizers e.g. stress / poor coping skills

Attitude e.g. pro-offending, hostile, negative

Static

Static Protective Factors might include:

Capacity to reflect on own feelings and thoughts History of at least some good relationships Capacity to actively share feelings with others Capacity to feel empathy with others' feelings Resilience



Dynamic

Dynamic Protective Factors might include:

Good relationship(s) in the present

Communicative (talking, writing, drawing)

Able to reflect emotionally

Able to ask for and use help

Clear plans or wishes for the future

Previous plans not carried out (but care must be taken not to assume this means they won't this time)

Low Risk: Protective Factors





How to assess risk? 4 P's

Predisposing

Genetics, pre and perinatal complications, learning difficulties, temperament, low selfesteem, difficult relationships with family, attachment

Precipitating

Loss related stresses, divorce, bullying, abuse, other life events, failure at school, significant recent events

Perpetuating (maintaining)

Ongoing stressful live events, unsuitable educational placement, disengagement in treatment

Protective

Physical health, good family relationships, good social support, socio-economic status

Stages of Change University Hospitals Bristol **NHS NHS Foundation Trust** <u>reminder</u> Precontemplation No intention of changing behaviour cancer Relapse Contemplation Fall back into old Aware a problem patterns of behaviour exists. No commitment to Upward Spiral - Learn from action **Preparation** Maintenance Sustained change -Intent upon new behaviour taking action replaces old **Action** Active modification Respecting everyo of behaviour Embracing change **Recognising succe** Working together Our hospitals.