Managing the transition from adolescent to young adult

Louise Soanes
Teenage Cancer Trust Nurse Consultant for Adolescents & Young Adults

The Royal Marsden NHS Foundation Trust, London
Cultural context of age group
Multiple transitions from child to adult

- Determined by:
  - Age or development
  - Systems – health & education
  - Traditional markers – leaving home, forming relationships, getting a job
Boundaries of adolescence & young adulthood

- Adolescence defined by (WHO 2010) between the ages of 10 -19 years

- Sociological five key demographic milestones milestones of adulthood
  - completing school
  - leaving home
  - becoming financially independent
  - marrying
  - becoming a parent
The Inbetweeners

- Erikson (1968) identity, instability, self-focus and feeling in-between
- Keniston (1971)
  - adolescence as a time of immaturity and youthful behavior
  - young adulthood as a phase of reaching full maturity and an established place in society.
- youth as an in-between phase where young people were yet to have found their own relationship to society, romantic partners and are unsure of their choice of career / further education

Modell et al (1976) adult status is based on a combination of personal qualities and social roles rather than a demographic set of criteria
New age, new stage?

Emerging adulthood (Arnett 2000)

– accepting responsibility for oneself
– making independent decisions
– becoming financially independent
– standing alone as a self sufficient person
– developing greater concern for others
– avoiding behaviour that might harm others
Discourse on emerging adulthood

Claim
- the transition to adulthood is
  - longer
  - more complex
  - pluralised and uncertain
  - more individual
  - more open to risks and hazards as well as opportunities (Arnett 2000)

Counter claim
- ethnocentric, middle class and gender bias (Douglass 2007)
- combination of personal qualities and social roles (Shannan et al 2008)
- emerging adulthood is not a universal stage but depends on the cultural context in which young people develop and the social institutions they encounter (Bynner 2005)
What's the issue?

• ‘Many countries fail to put sufficient emphasis on the special needs of adolescents....they are either treated the same as children or share facilities with adults...’ (Kleinert 2007)
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Managing the transition from adolescent to young adult. EBMT 2013
What is needed to provide age appropriate care?

- Access to expert disease specific care
- Access to clinical trials
- TYA MDT
- Philosophy of care that strives to ensure achievement of holistic potential beyond diagnosis - medical, social, educational, psychological
- Information giving and approach tailored to individual needs of patient and family -non-judgemental
- Age appropriate environment + ability for family to be present
- Schooling/health education
- Psychological support
- Financial support
- Peer support/mentoring
Implications for service delivery

- ‘Services need to be responsive to the range and characteristics of transitions, and thus sensitive to the perspectives of young people (Gorter et al 2011)

- “The cut off for adult services at 18 is illogical and damaging” respondent in patient survey

- Beyond risk assessment: integrating risks and growth
Needs of those involved
Adolescents & young adults

- AYA personal characteristics & circumstances
- Preference for bio-psychosocial model (Kraus de Camargo 2011 & Kingsnorth 2011)
- Individual or group programme
- Value of the key worker (Kingsnorth 2011)
- Patient involvement in the design of the service / programme
Healthcare professionals

- Knowledge, experience (and liking) of AYA
- Communication skills (patients & colleagues)
- Understanding of transitional care
- Other demands
- Lack of evidence

(Huang 2012)
Wider influences on the effectiveness of transition (Crowley et al 2010)

- Individuals, families & health social care providers
- Environmental
- Socioeconomic
- Bio-medical approach focusing on control disease & fixing impairments
Barriers to transition

- Lack of evidence of effectiveness of transition programmes (Watson et al 2012)
- Limited staff training
- Lack of identified staff responsible for transition
- Financial barriers
- Anxiety on part of paediatricians, adolescents and their parents
- Lack of tools to assess adolescent’s & family’s readiness for transition
- Aging population
Building the service & team (with no extra resources)

- Planning
- Facilitating the process
- HCP as facilitator
- The point of transfer
- After transfer
Best principles (TYAC in print)

- Timing – anticipate transition 1-3 years ahead of it happening
- Patient/family involvement
- Key worker support
- MDT handover
- Ensure all services transition at the same time (and ideally to the same place).
- Treatment summary/care plan
- Joint/transition clinic
- Transition policy
- Professionals to work across boundaries
- Health promotion/education role
- Effective communication and collaboration
One transition model for HSCT survivors

- Early teens
  - Paediatric lead service – safe & familiar
  - Focus on the teenager rather than the parent
  - End of treatment summary and care plan
  - Plan for transition two years in advance

- 16 years – Teenage & Young Adult Clinic
  - Adult led service (with paediatric input) – very different approach
  - Holistic needs assessment tool introduced
  - Teenager seen on their own
  - Forward rather than backward looking – focus changes to lifestyle, responsibility, choices, future consequences of decisions
  - Open discussion on potentially normal activities of adolescence
  - Self management
Transition for HSCT survivors phase 2

– 18 years
  – Parents encouraged not to attend at all (as appropriate)
  – Complete focus on young adult
  – Possible transfer to primary care – can very be challenging.

– 25 years
  – Possible transfer to primary care (if not already done)
    transfer to adult services
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The Teen and Young Adult Worry and Memory Thermometers 16-24

Instructions:
• Please follow steps one to five and answer the questions.
• You can tick as many boxes as you like on page 2.
• Please ask someone if you need any help filling the questionnaire in.

1. Please circle the number (0-10) that best shows how much you have been worrying or feeling upset about things in the past week, including today. You can choose ANY number.

2. Please circle the number (0-10) that best shows how much you have had trouble with your memory and learning in the past week, including today. You can choose ANY number.

3. How you feel – you can tick more than one box in each section. Please tick how you have been feeling over the past week, including today:
   - Feeling happy
   - Feeling nothing at all
   - Lack of motivation / no motivation
   - Feeling confident
   - Feeling different to others
   - Lack of ambition
   - Feeling like I’m coping well
   - Worried about the way I look
   - Distressing thoughts / images that pop into my head
   - Feeling sad
   - Feeling bad about myself
   - Having nightmares
   - Feeling worried
   - Feeling lonely
   - Feeling scared of things
   - Getting angry
   - Feeling panic

Please tick anything that has been a problem for you over the past week including today: Practical issues:
   - Where I am living
   - Money
   - Getting around
   - Getting on with my parents
   - Making friends
   - Getting into trouble
   - Getting on with other adults
   - Getting a boyfriend or girlfriend
   - Worried about getting onto a course / job
   - Getting on with other people my age
   - Socialising with my friends / at university / at work
   - Getting on with my brothers/sisters
   - Being bullied

Please tick anything that has been a problem for you over the past week including today: Problems with my body:
   - Pain
   - Sleeping
   - Fertility
   - Nausea
   - Difficulty breathing
   - Problems with mobility such as walking
   - Fatigue
   - Eating

4a. Are there any other things you have been worrying or feeling upset about in the past week including today? If so, please write in the space below:

4b. If you would like to describe any of the problems you have ticked in more detail, please tell us here:

5. Finally, would you like some help with any of these problems?
   - Yes
   - No
So how does it work in practice?
Challenges

- Sudden transition - relapse is not an ideal time for transition to commence.
- Flexibility - sounds good but can you always do it i.e. maturity, palliative, end of life & relapse?
- Non engagement / non – compliance - leave the door open
- Reluctance to transition – AYA offer visits/introduction to new clinical setting with key worker etc. Health & social care professionals - they are human & might need support too!
- Confusion - ensure agreed protocols and policies are developed to delegate roles and responsibilities across service providers
- When do you stop transition?
Thank you for listening - any questions?