

# Clinical Problems/Challenges! in Adolescent Medicine



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# Talk Outline

- Background
- Adolescent medicine
- Transition
- Young person Friendly Health Services



# What is an adolescent?

When and why did you stop feeling like a child?



When did you start feeling like an adult?

# Stage – not an Age!!

- WHO 10 to 19 years
- Some UK paediatric services 16 years!
- Youth
  - 15-25 yrs
    - European Union
    - Australia
  - 15-24 yrs
    - New Zealand
    - Canada



# Emerging Adulthood

(Arnett JJ 2000)

- Identity exploration
- Self-focus
- Instability



- No longer “settle down” aspirations
- “Yes – but not yet”
- Less restricted by gender roles, economics
- Delay in taking up traditional adult responsibilities
- Less dependent than adolescents
- Less committed than adults

# Adults vs emerging adults

- Similar logical competencies

BUT

- Different social and emotional factors

therefore

- Differences in decision and risk taking



# Importance of Context

- 18 year old female who is living with her partner and pregnant with her 2<sup>nd</sup> child

Vs

- 18 year old female who is studying at university and living with her parents
  - 16 and in education – paediatric care
  - 16 and not in education – adult care
- eg Singh SP et al, 2008 (UK)*

# So, Why Bother?

Arguments for specific focus on adolescents

- Numbers
- Specific presentation & epidemiology of disease
- Health services use
- Specific needs in the management of illness and health
- Impact on Adult health...

# Impact on adult health

- Health risk behaviours are adopted in adolescence and track into adult life +/- enter next generation via parenting
- Antecedents of adult ill-health during adolescence: eg mental health, diet, exercise, cardiovascular risk, smoking, injury
- Self-management patterns are set down in adolescence e.g. health care utilisation, chronic disease self-management
- Childhood-onset disease and/or associated morbidities in adulthood

# Morbidity and Mortality

- A third of renal transplants lost during transfer to adult care

*Watson AR 2000*

- 80% 17 year olds with JIA had active disease

*Shaw KL et al 2005*

- Mortality adolescent JSLE = 2x adult SLE

*Tucker LB et al 2008*

- Mortality of adolescent onset cancer worse than childhood/adult onset

*Bleyer A 2005*

# Inequalities in Young People's Health

Report from the Health Behaviour  
In School-Aged Children  
2005/06 Survey in 41  
countries

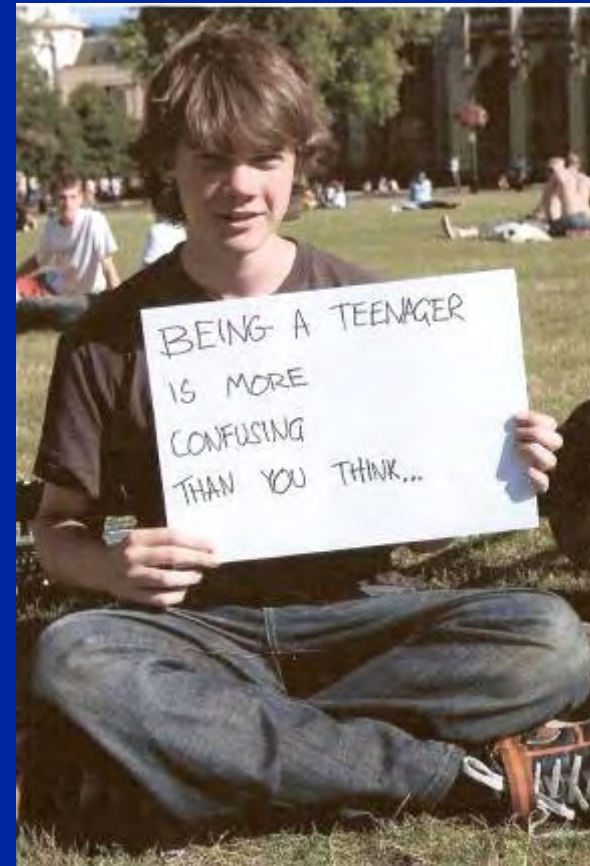
Currie et al, 2008. WHO,  
Copenhagen  
Health Policy for Children  
and Adolescents, No. 5

<http://www.euro.who.int>



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# Principles of Adolescent Medicine

1. Development

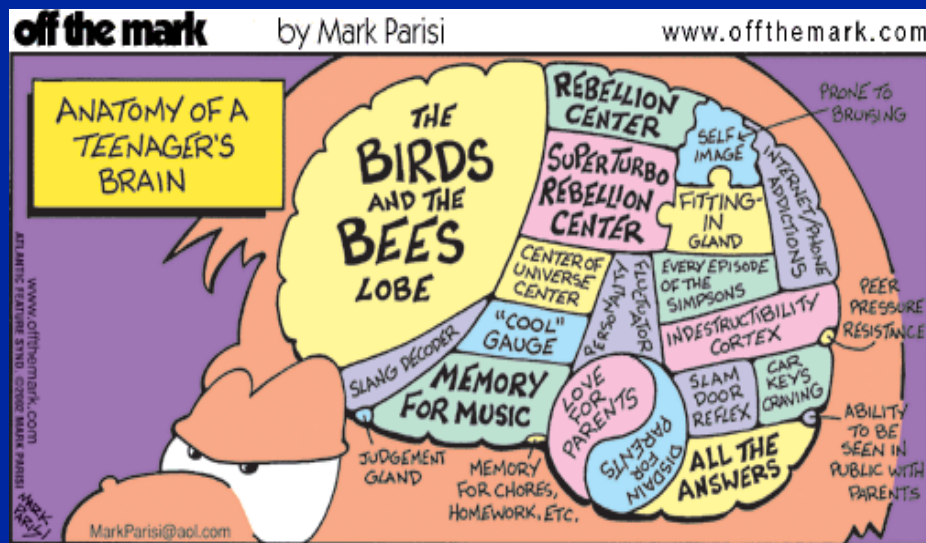
2. Resilience

a. To consolidate his/her identity – personal and sexual

b. To establish relationships outside the family

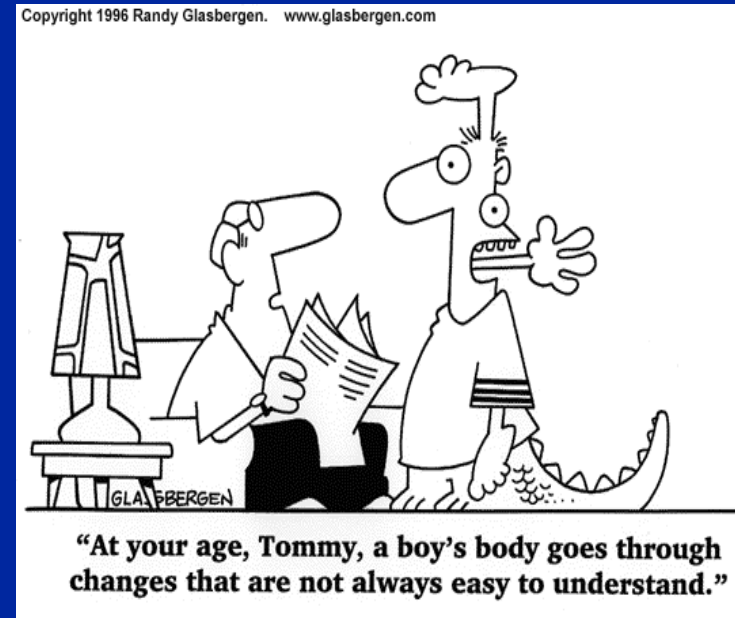
c. To achieve interdependence with parents

d. To find a vocation

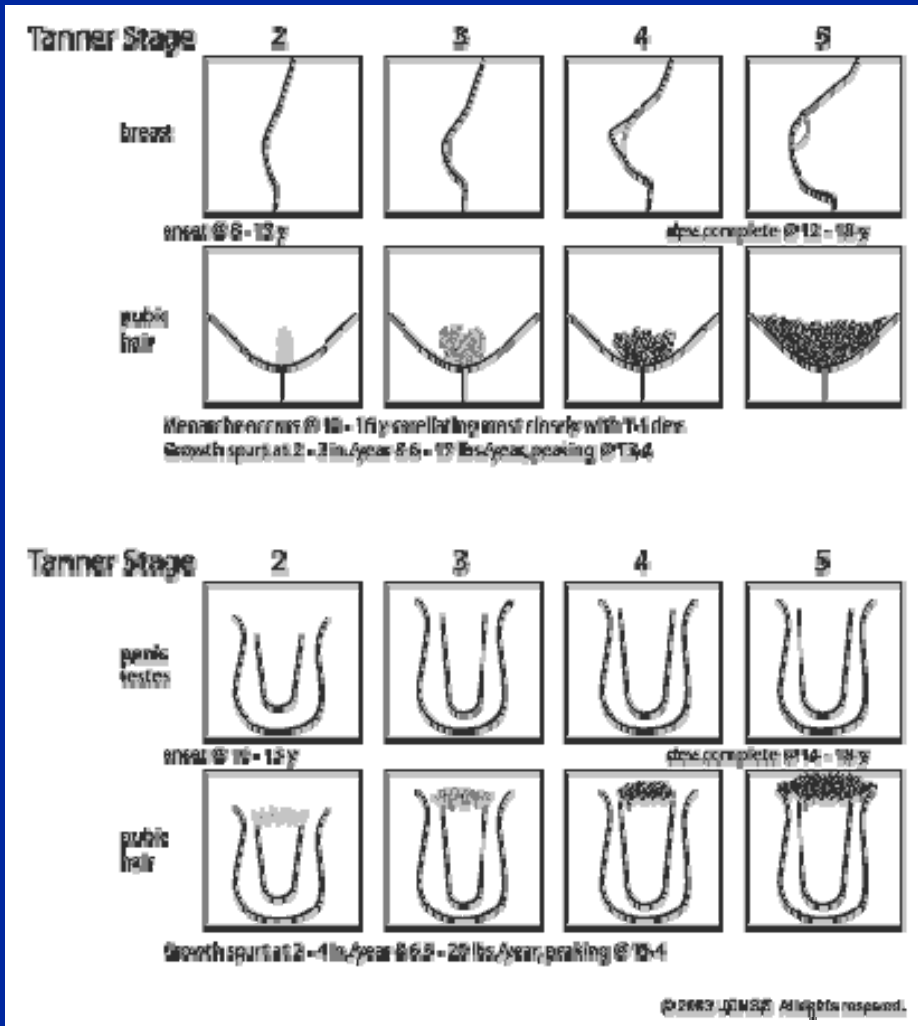


# Developmental/Adolescent Medicine

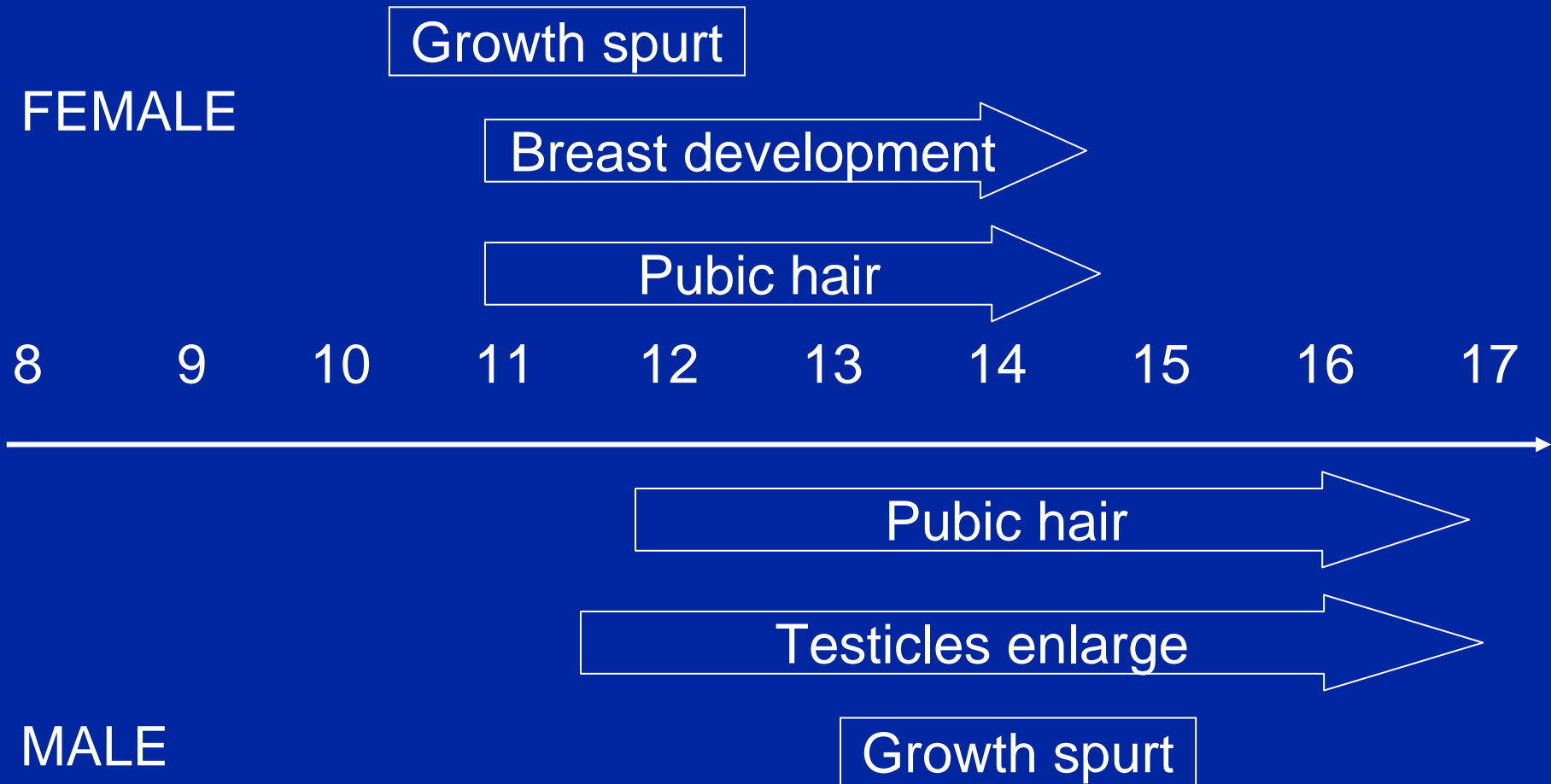
- Early, mid, late adolescence
- Biological/physical, cognitive, psychosocial
- Inter-relationships
- Potential for delay in context of chronic illness
- Potential for fast tracking



# Physical/Biological Development



# Adolescent Development: Puberty



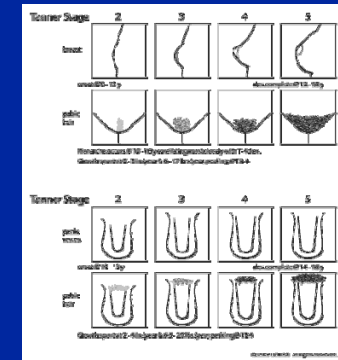
# Adolescent Development: Physical

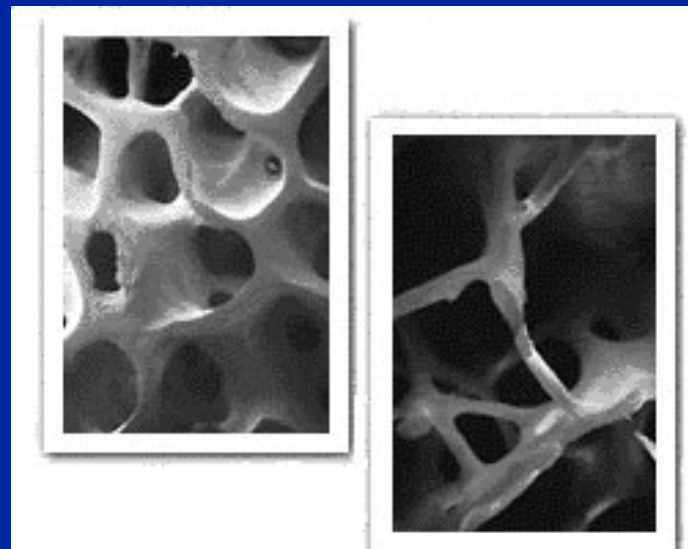
- 100 case notes  
13-18 yr old in-patients in Children's  
Hospital  
- Puberty 12

*Yeo et al, 2005*

- Paediatricians and adult physicians  
poor at monitoring growth and  
pubertal development

*Ghosh S, 1998; Lek 2008*





40% of adult bone mineral density is accrued in adolescence

# Adolescent Brain Development

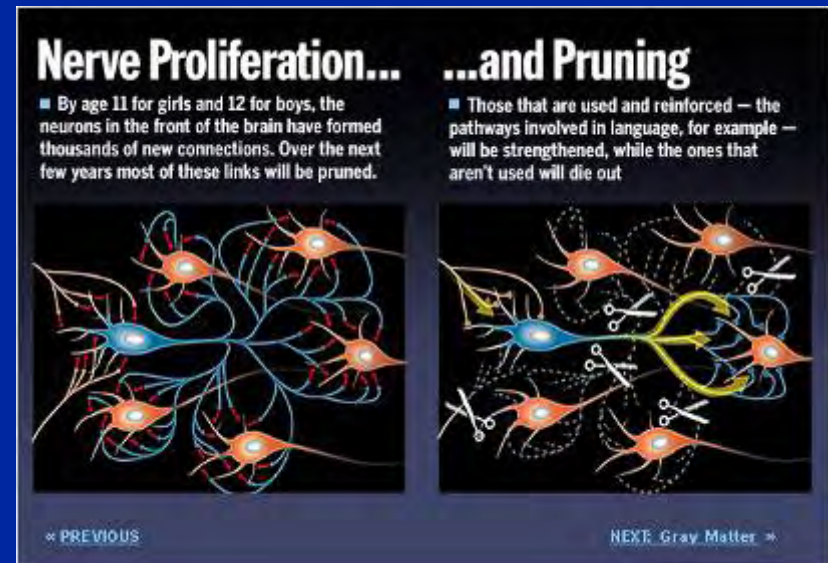
## 1. Brain

- Regulation of behaviour and emotion
- Perception and evaluation of risk and reward

## 2. Behaviour

## 3. Cognition

- Different timetables
- Biological control



*Steinberg L, 2005*

# Adolescent Cognitive Development

Early

Middle

Late

Puberty heightens emotional arousability, sensation-seeking, reward orientation

Period of heightened vulnerability to risk-taking and problems in regulation of affect and behaviour

Maturation of frontal lobes facilitates regulatory competence

*Steinberg L 2005*

# Result of Developmental Mismatches

Wanting to be treated "more like an adult"

yet have difficulties....

- expressing thoughts and feelings
- taking another's point of view
- anticipating consequences of one's actions
- asking for assistance

# Psychological development

- Abstract thinking
- Body Image
- Sense of self
- Sexual identity



# Development of adult abstract thinking

- Impact on adherence of reduced ability to plan and prepare using abstract concepts
- Difficulty in imagining the future
- Self-concept as being “bullet-proof”
- Need to use immediate > future motivators
- Potential for delay/regression in chronic illness

# Concrete vs Abstract Thinking

- Concrete thinking

- *You said I'd get ill if I missed my asthma inhalers. But I forgot them twice and I stayed fine so I don't need them any more*



- Abstract Thinking

- *I missed my inhalers a couple of times but I think I got away with it because I wasn't doing much exercise. I think I'll still need them in the future if I'm doing lots of exercise or in cold weather*

# Adolescent Logic is Different!



I DDM, 10-20 years

- 10-39% health risk behaviours
- Physical risks were known BUT perceived to be higher for peers than self!

*Frey MA et al, 1997*

- 57% of non-smoking cancer survivors (10-18 years) reported some intention to use tobacco!

not associated with perceived vulnerability to health risks!

*Tyc VL et al, 2006*

# Chronic illness and Psychological Development

- Infantilisation
- Adoption of sick role as personal identifier
- Egocentricity persists into late adolescence
- Rejection of medical professionals as part of separation from parents

# 3. Social Development

- Individuation
  - Family
  - Peers
  - Intimate relationships
- Exploratory/risk behaviours
- Development of educational then vocational capacity
- Financial independence



# Health Risk Behaviours

- Young people with a chronic condition  
(n=760, 16-20 year olds)

More likely to

- Smoke daily
- To be current cannabis users
- To have performed violent or antisocial acts
- Report 3 or more risk behaviours

*Suris JC et al Pediatrics 2008*

- ¼ to 1/3 substance use – no private time with Dr

*Kappahn CJ, 1999*

- Substance use - associated with non-adherence

*Lurie 2000; Stilley CS 2006*

# Developmental Delay in Young Adulthood

Significantly delayed milestones in  
childhood onset diseases:

- autonomy
- psychosexual
- vocational and
- social development

*Britto MT, 1998; Stam H et al, 2006; Lyon M et al 2006*

# Resilience Framework

- Capacity of the individual or community to resist or “bounce back” in spite of significant stress or adversity

*Newman 2002*

- Risk and risk factors
- Protective factors
  - Resources
  - Competencies
  - Talents
  - Skills



# Getting Into Adolescent HEADSS!



H - Home

E - Education,

A - Activities/ambitions

D - Drugs/alcohol

S - Sex

S - Suicide/affect

*Goldenring 2004*

NO psychosocial assessment in 62%  
case notes

13-18 year old in-patients  
*Yeo et al, 2005*

Suboptimal in rheumatology case  
notes

*Robertson LR et al 2006*

# Proactive and Anticipatory Approach

- n=313 young people (11 to 21 years)
- Few adolescents *initiated* discussion of sexual issues
- Discussion related to
  - Absence of a parent
  - Positive attitudes/comfort

*Merzel CR et al J Adol Health 2004*



# The Importance of Asking!

N=358

11-16 year olds

If discussion of a sensitive health topic:

- More positive perception of provider (OR3.62)
- More likely to have their worries eased (OR=2.13)
- More likely to be allowed to make decisions re treatment (OR=2.51)
- More likely to report taking responsibility for treatment (OR=2)



*Brown JD 2009*

# Not Just Asking, Assessing & Advising

Milne B, Towns S. J Paed Child Health, 2007

Routinely asked Qs using the 5As brief intervention strategy	All or most of the time N=57 (%)
<b>Ask</b> adolescents if they smoke	31 (54%)
<b>Assess</b> adolescent readiness to quit	25 (44%)
<b>Advise</b> adolescents to quit smoking	33 (58%)
<b>Assist</b> adolescent with quit strategies	9 (16%)
<b>Arrange</b> follow-up for adolescents	10 (18%)

# Resilience

## Protective Factors in the Health Care Setting: Knowledge



### Knowledge Deficits

- Juvenile Idiopathic Arthritis: *Berry 1993, Shaw KL, 2004*
- Cancer: *Kadan-Lottick NS, 2002*
- Congenital heart disease: *Dore A, 2002*
- Haemophilia: *Lindvall K 2006*

### Disclosure issues

- *Shaw KL, 2004*
- *Telfair J, 1994*

Information gives young people

- Choice
- Reference points

Health led  
Resonant with their lives  
Up to date

Chance to dispel myths

# Resilience

## Protective Factors in the Health Care Setting: Skills

- Communication
- Negotiation
- Goal setting
- Problem solving
- Decision-making
- Self-management
- Information seeking
- Health care utilisation
- Disclosure



**Top tips** 

**Before your appointment** 

- Write down your two or three most important questions.
- List or bring all your medicines and pills - including vitamins and supplements.
- Write down details of your symptoms, including when they started and what makes them better or worse.
- Ask your hospital or surgery for an interpreter or communication support if needed.
- Ask a friend or family member to come with you, if you like.

**During your appointment**

- Don't be afraid to ask if you don't understand. For example, 'Can you say that again? I still don't understand.'
- If you don't understand any words, ask for them to be written down and explained.
- Write things down, or ask a family member or friend to take notes.

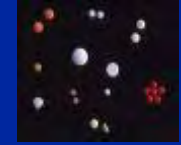
**Before you leave your appointment** 

- **Check that:**
  - you've covered everything on your list
  - you understand, for example 'Can I just check I understood what you said?'
  - you know what should happen next - and when. Write it down.
- **Ask:**
  - who to contact if you have any more problems or questions
  - about support groups and where to go for reliable information, and
  - for copies of letters written about you - you are entitled to see these.

**After your appointment, don't forget the following** 

- Write down what you discussed and what happens next. Keep your notes.
- Book any tests that you can and put the dates in your diary.
- **Ask:**
  - 'what's happening if I'm not sent my appointment details,' and
  - 'can I have the results of any tests?' (if you don't get the results when you expect - ask for them.) Ask what the results mean.

© 2011, 2014, 2015, 2016, 2017, 2018, 2019, 2020, 2021, 2022, 2023, 2024, 2025, 2026, 2027, 2028, 2029, 2030, 2031, 2032, 2033, 2034, 2035, 2036, 2037, 2038, 2039, 2040, 2041, 2042, 2043, 2044, 2045, 2046, 2047, 2048, 2049, 2050, 2051, 2052, 2053, 2054, 2055, 2056, 2057, 2058, 2059, 2060, 2061, 2062, 2063, 2064, 2065, 2066, 2067, 2068, 2069, 2070, 2071, 2072, 2073, 2074, 2075, 2076, 2077, 2078, 2079, 2080, 2081, 2082, 2083, 2084, 2085, 2086, 2087, 2088, 2089, 2090, 2091, 2092, 2093, 2094, 2095, 2096, 2097, 2098, 2099, 2100



# Skills in Adherence

## Choice of Trigger Questions

- Do you take your medicine every day?

VS

- When was the last time you forgot?
- Tell me about a typical day for you? How do you manage to fit taking your medicine?
- What makes it difficult to take your meds?

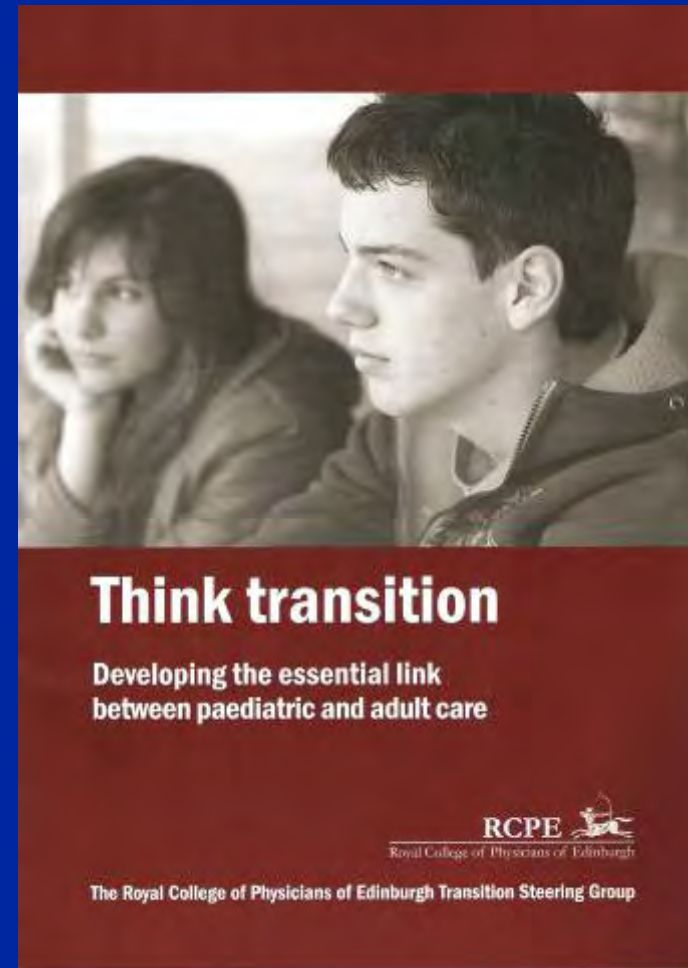
# How Do WE Promote Positive Youth Development in Healthcare

- Raise awareness of their developing strengths and role they can play in their own health and well-being
- Motivate and assist adolescents in taking on responsibility for their own health
- Actively promote their strengths
- Model respect and kindness towards young people
- Convey belief in young people

*Duncan PA et al, J Adol Health 2007*

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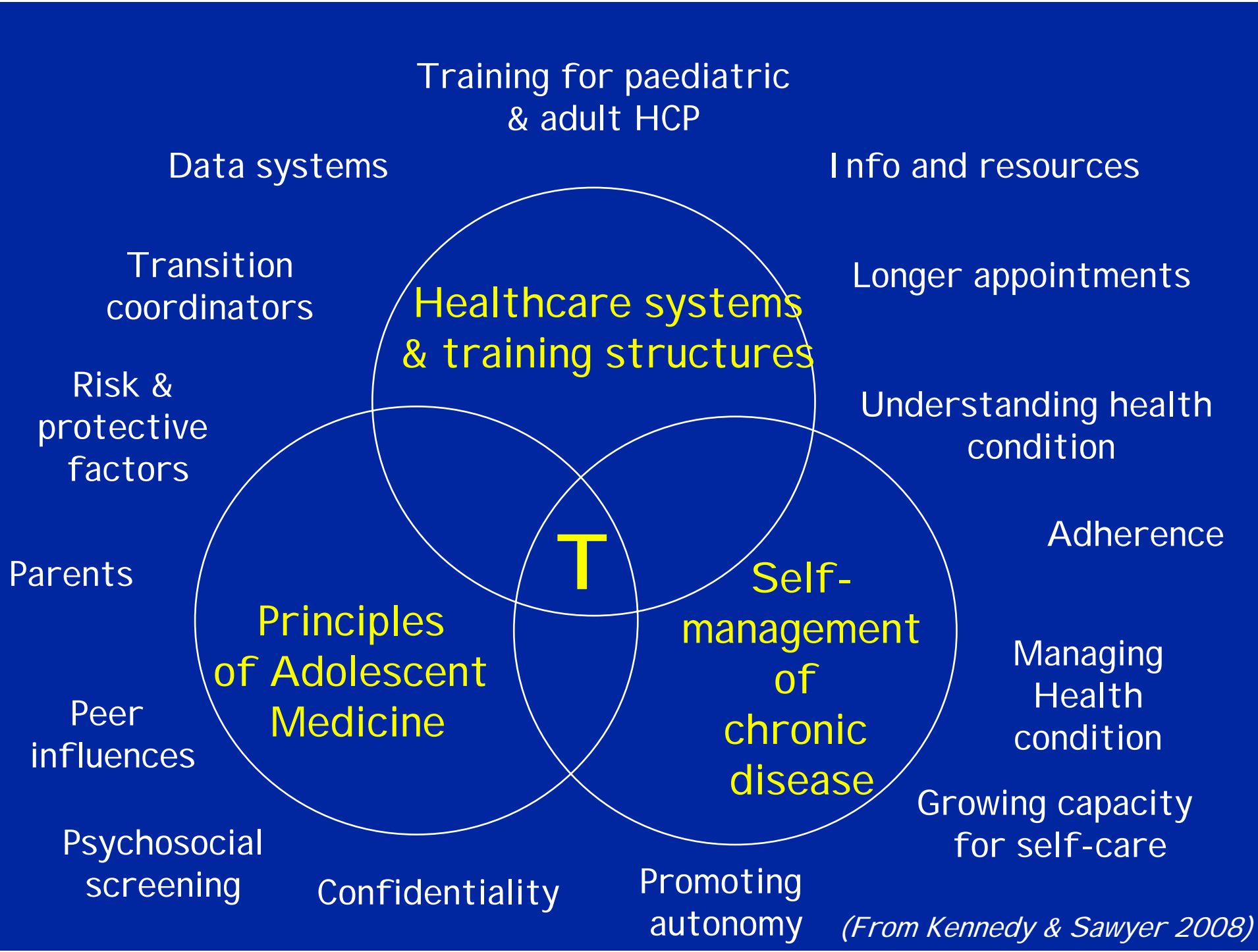
# Transition is a Process



11-12 yrs



Transition is the moment of change



Training for paediatric & adult HCP

Data systems

Info and resources

**Healthcare systems & training structures**

Longer appointments

Transition coordinators

Understanding health condition

Risk & protective factors

Adherence

**T**

**Principles of Adolescent Medicine**

**Self-management of chronic disease**

Parents

Managing Health condition

Peer influences

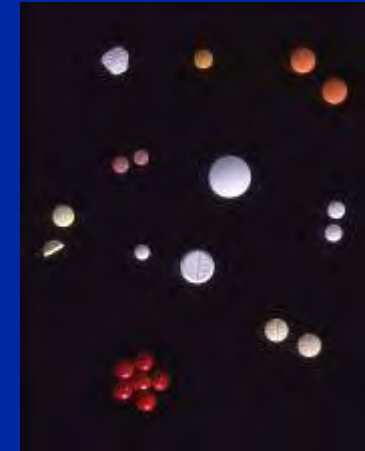
Growing capacity for self-care

Psychosocial screening

Confidentiality

Promoting autonomy

*(From Kennedy & Sawyer 2008)*



# Transition

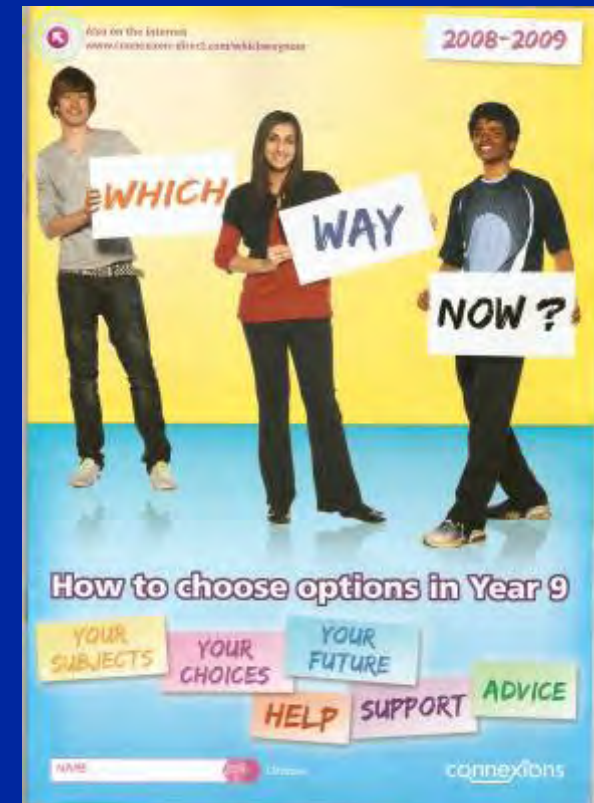
- Medical
- Psychological
- Social
- Educational
- Vocational



# Multidimensional Transition

e.g. Young People with CF

- NO change in clinical status post transfer
  - BUT ...↑ number NOT in school/job
- 7.9% pre vs 31.5% post (p=0.005)
- Median age: 23 yrs



*Dugueperoux et al 2008*

# Service Provision

	"Transition/adolescent Clinic"	
<b>UK</b>		
Rheumatology	18%	<i>McDonagh JE 2000</i>
Endocrine	56%	<i>Kirk J &amp; Clayton P 2006</i>
Diabetes	53%	<i>Jefferson 2003</i>
Gastro	A third	<i>Davies &amp; Jenkins 2003</i>
<b>International</b>		
Paed Dialysis	A third	<i>Bell L 2007</i>
USA: CF	28% (programme)	<i>McLaughlin SE 2007</i>
GUCH	A third (programme)	<i>Hilderson D 2009</i>

Advocacy  
For  
Young person



Remain  
Inclusive  
Of  
Parents

# Parental Issues in Transition

- Impact of transition greater on parents than young people with haemophilia

*Geerts E et al 2008*

- A third of health professionals reported parental difficulties during transition

*Shaw KL, 2004*

- Discrepancies re: “right age” and perceived importance of transitional issues between health professionals and parents

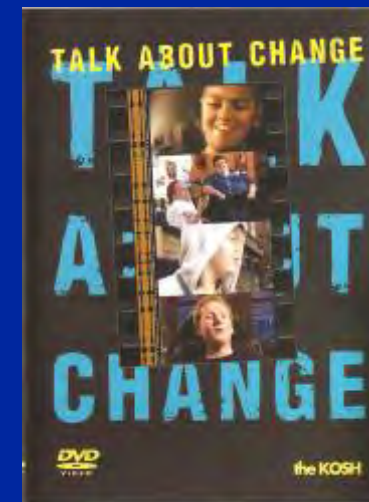
*Geenen SJ, 2003*

- Overprotection

*Durst CL, 2001; Shaw KL, 2004;*

# "Talk About Change"

- Different cultures of care
  - *Rosen DS 2005*
  - Lack of preparation for different service provision
    - *Shaw KL, 2004*
    - *Heslop P, 2002*
    - *Morris J, 2002*
    - *Dean J, 2003*
- Reduction in services post transfer
  - *CSCI, 2007*
  - *Shaw K, 2004*
  - *Fiorentino L, 1998*



# Role of Adult Physician



Young people prefer to meet adult Drs/team prior to transfer

- *Mixed: Tuchman LK 2008*
- *IDDM: Scott 2005; Kipps 2002*
- *JIA: Shaw KL 2004*
- *CF: Nasr 1992; Abdale 1994; Landaw 1995; Boyle 2001; Steinkamp 2001;*
- *Heart transplant: Anthony SJ 2009*

Higher rates of adherence to appointments in units where young people met adult Drs prior to transfer

*Kipps 2002*

# Evidence of Benefit Of Transitional Care "Programmes"

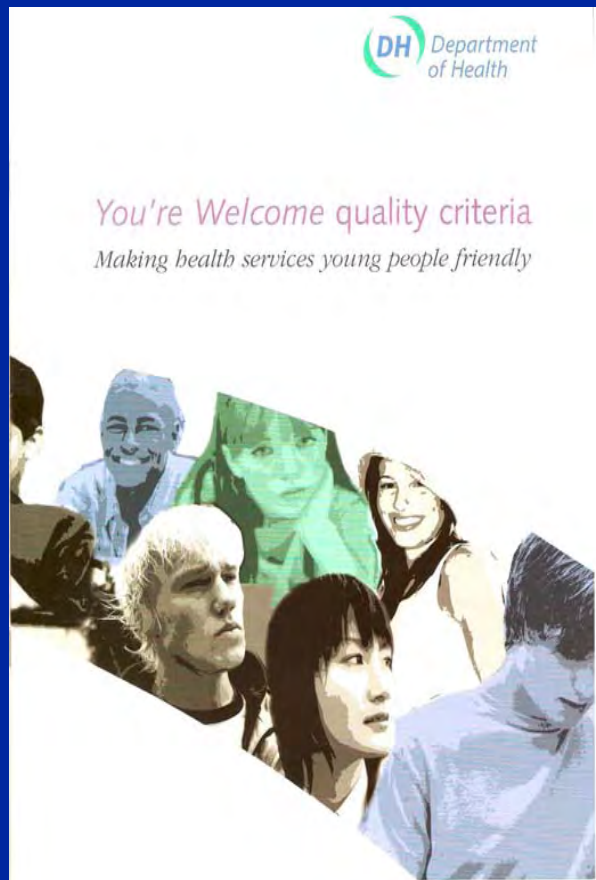
- Patient satisfaction  
*(CF: Bronheim, 1989; Steinkamp G, 2001; Zack J, 2003.  
JIA: Shaw 2007)*
- Parent satisfaction  
*(JIA: Shaw KL et al 2007)*
- Improved disease control  
*(DM: Salmi J, 1988; Orr DP, 1996)*
- Improved documentation of adolescent issues  
*(JIA: Robertson L, 2006)*
- Improved health related quality of life  
*(JIA: McDonagh 2007)*
- Disease knowledge  
*(JIA: McDonagh 2007)*
- Vocational readiness  
*(JIA: McDonagh 2007)*
- Adherence to appointments  
*(JIA: Rettig P, 1991; Vanelli M, 2004. Diabetes: Kipps 2002)*

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# Young Person Friendly Health Services



[www.who.int](http://www.who.int) 2002

# Differences between paediatric and adult health services

- Age range!
- Culture of care
- Growth and development
- Consultation dynamics
- Communication skills
- Generic health issues
- Confidentiality issues
- Role of parents/family/peers
- Education/Vocation
- Tolerance of immaturity
- Procedural pain management
- Spectrum of disease
- Impact of disease
- Legislation
- Service Provision
- Health care utilisation
- Appointment duration
- Extent of physical examination
- Continuity
- Trainee supervision
- Consultant accessibility
- DNAs



# Promoting Autonomy

eg Opportunity to see the Dr on  
their own

- N=51 Drs routinely seeing adolescents
- 23% routinely offer to see young people on their own
- 21% never offered
- 30% considered it "not essential"

*Baverstock A et al, (abstract),  
2009*



# Promoting Autonomy

eg Opportunity to see the Dr on their own

- Considered “Best practice and feasible” by adolescents with JIA, parents and professionals

*Shaw KL et al, 2004*

- Baseline predictor of improvement in HRQoL

*McDonagh JE et al 2007*

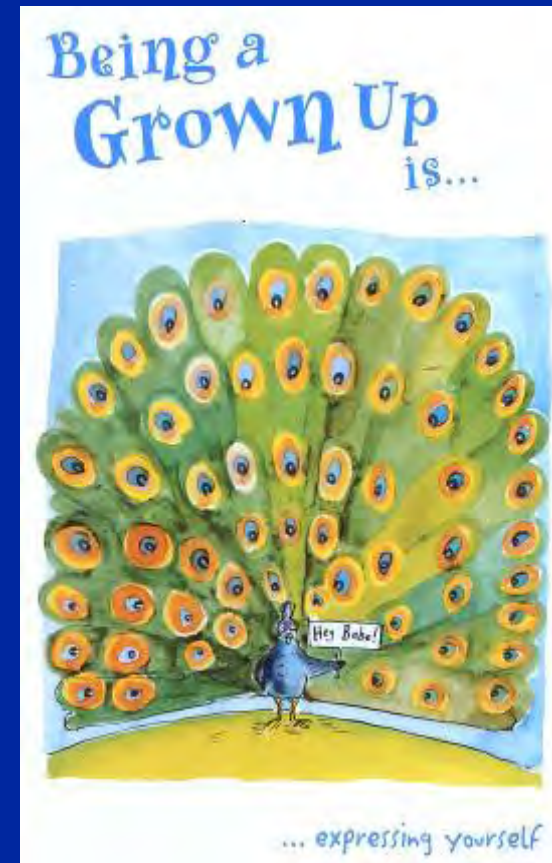
- Determinant of attendance at 1 adult clinic (GUCH) appointment (OR 6.59)

*Reid GJ et al, Pediatrics 2004*



# Independent visits

- Choice of individual young person
- Choice of chaperone
- Can be part of visit
- Assurance and explanation of confidentiality
- Skills
- Clearly advertised
- Explanation for parents



# Confidentiality Concerns

- 58% 13-15 year olds (n=1045)

*Burack R, 2000*

- F>M  
Older > younger

*Carlisle J, 2006*

Adolescents who report

- Psychological distress
- Unsatisfactory communication with parents
- Health risk behaviours

are more likely to cite confidentiality concern as a reason for forgone health care

*Lehrer JA et al, 2007*

# Opportunity of Physical Examination

## Opportunity

- to teach re body, health, puberty
- to reassure normal findings
- For YP to disclose

Always expose upper thighs and upper arms



- Accessibility
- Publicity
- Confidentiality and consent
- The environment
- Staff training, skills, attitudes and values
- Joined up working
- Monitoring, evaluation and involvement of young people
- Health issues for adolescents
- Sexual and reproductive health services
- Child & Adolescent Mental Health Services

*England: DoH 2007*

*Scotland: [www.walk-the-talk.org.uk](http://www.walk-the-talk.org.uk)*



# Professional Attitudes

Perceived attitude towards adolescents  
as barrier to communication

*Beresford & Sloper 2003*

*"One physician who did not screen at all  
(for risk-taking behaviours) believed  
strongly that he would be interfering  
with the parent-child relationship if he  
engaged in enquiries regarding risky  
behaviours"*

(NB Mean age = 18yrs!!)

*~ Britto MT et al, 2000*

# Selectivity of Information Provision

## Sexual Health

- 100% health professionals reported discussion re infertility with male adolescents with CF  
BUT only 38% discussed importance of condoms

*Sawyer SM et al, 2001*

- Disease information biased towards pregnancy/heredity rather than sexual activity
- Disease specific > generic information
- Need information AND access!

# The Education Challenge!

*Best Practice – but only  
feasible in a few UK  
hospitals:*

Professionals  
knowledgeable in  
transitional care

*Shaw KL et al, 2004*



Main barrier to delivery of  
transitional and/or adolescent  
health care: lack of training

*Eg Blum RW 1990;*

*Viet 1996;*

*McDonagh JE et al 2004, 2006;*

*Dieppe C 2008;*

*Peter NG 2009*

# Benefits of training in adolescent health

- Sustainable, large improvements in knowledge, skill and self-perceived competency
- Improvements sustained 12m to 5 yrs

*Sanci L et al. 2000, 2005*

- Higher rates of desired clinical practices eg confidentiality, health screening

*Marks A, 1990 ; Middleman AB 1995;  
Evans T, 1998; Sanci L 2000; Britto M 2000; Lustig JL 2001;*

- Greater number of adolescents seen

*Key JD 1995*

- Greater tendency to engage in continuing education in Adolescent Health

*Key JD 1995 Sanci L 2005*

# Curriculum

- Healthy development – Psychosocial development / puberty and growth
- Legal Framework – consent & confidentiality - ethics & safeguarding
- Consultation & Communication
- Health Promotion and Advocacy
- Chronic Conditions & Transition
- Common Medical conditions
- Concordance / Adherence
- Youth Friendly Services
- Sexual & Reproductive Health
- Substance Abuse and Misuse
- Self-Harm and Mental Health
- Overweight & Underweight - obesity and eating disorders

# Adolescent Health Training Resources

- European:

European Teaching Effective Adolescent Care & Health

[www.euteach.com](http://www.euteach.com)

[www.e-lfh.org.uk/ahp](http://www.e-lfh.org.uk/ahp) (UK)

- USA:

- <http://www.usc.edu/adolhealth/>

- Australia:

- <http://www.caah.chw.edu.au/resources/#03>



**Adolescent Health**  
e-Learning for Healthcare Professionals

Adolescent Health is an exciting e-learning project designed to improve the health outcomes and care of young people in the UK.

Delivered in partnership with The Royal College of Paediatrics and Child Health (RCPCH), The Royal College of General Practitioners (RCGP) and e-Learning for Healthcare (e-LH), Adolescent Health is available free to all healthcare professionals within the NHS.

Adolescent Health supports the Royal College's competency based curricula for junior doctors in training (ST1-CCST, FTSTAs & SpRd), as well as post training to acquire Continuing Professional Development (CPD) credits for registration and re-valuation and ongoing training of nurses and allied health professionals.

There are over 70 highly interactive e-learning sessions covering some 30 topics, delivered through a bespoke set of modules. The accredited materials have been written by subject specialists and clinical experts in their particular fields, and subjected to extensive peer review.

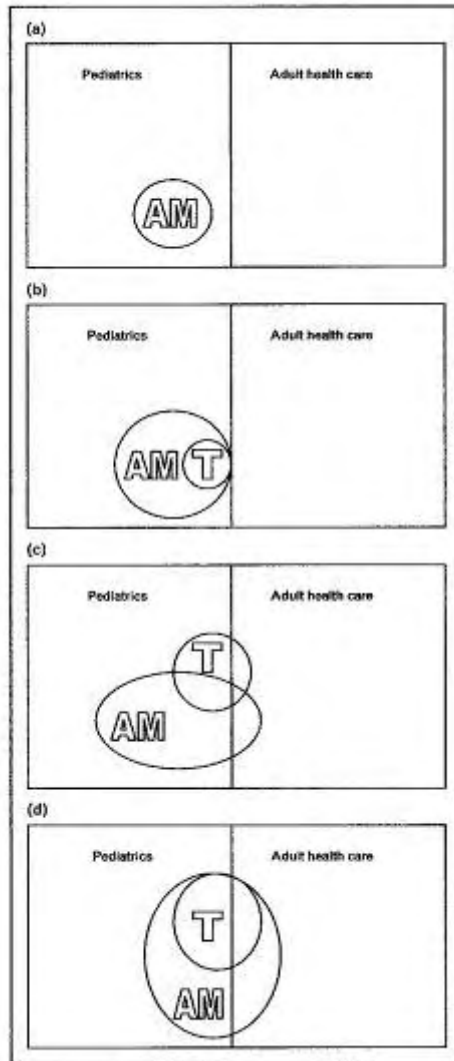
The e-learning sessions vary in length, with many around 20 minutes to fit in with busy work study lives.

Register today! Visit: [www.e-lfh.org.uk/ahp](http://www.e-lfh.org.uk/ahp)

For more information, please email the Adolescent Health Team at [ah.support@e-lfh.org.uk](mailto:ah.support@e-lfh.org.uk)



Figure 2 Diagrammatic representation of the emerging and growing awareness of both the principles of adolescent medicine and transition to adult healthcare within the practice of both pediatric and adult medicines



AM, adolescent medicine; T, transition.



Integration of adolescent medicine into both paediatrics and adult medicine will ensure developmentally appropriate care for ALL young people and their families



*Kennedy & Sawyer 2008*