NICE Quality Standards and the transition buddy: how to ensure young people are prepared for transition

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Overview

- Who to transition in CF?
- Is transition necessary?
- How to transition
- Identifying the challenges
- Making it work
- Coming of age
Who are we talking about?

Adolescence
10 years – 19 years (WHO)

Youth
15 years – 24 years (WHO)

16–19 year olds: n=943. UK CF Registry 2016
16–19 year olds: n=552. UK CF Registry 2007
UK population

- Children and adults with CF in the UK: \( n=10,461 \)
- Adults: 60%
- Median age: 20 years
- Median predicted survival: 47 years
- New diagnosis (all): \( n=247 \)
- Deaths per year: \( n=148 \)
- Median age at death: 31 years
- Adults in work or education: 66%  
  Retired: \( n=116 \) (2%)
- Mothers: \( n=71 \) live births, Fathers: \( n=48 \) assisted conception
Is transition necessary?

WHAT'S THE POINT?
Yes!

- Not big children
- Living an active adult life away from healthcare
- Actively involved in treatment decision making
- Co-morbidities
- Deteriorating health / aging / end of life
Why not stay in paediatric care?

- Improved survival for previously fatal childhood condition
- Pressures on tertiary care facilities – use of resources?
- Inappropriate (adults on the same ward as young children)
- Becoming adults outside hospital and dealing with adult issues
- Encouraging independence with treatment
- A sense of maturity and hope for the future

What is transition?

- ‘...the *purposeful, planned* movement of adolescents and young adults with chronic physical and medical conditions from *child-centred* to *adult-orientated* healthcare systems.’

- ‘Transition should be aimed at moving a person into adult life in such a way as to *promote* their *independence*....’

- ‘A period of transition from the *dependence* of childhood to adulthood’s *independence* and awareness of *interdependence* as members of a *community*.’

- ‘Being a parent is a lot like building a boat that you eventually will launch. The building process is gratifying, but so is launching the boat and seeing that what you’ve built can handle the seas. At some point as a parent, you’ve got to start getting your child ready to be launched’


*Department of Health (UK). Transition for children to adult care and support.* 2014.

*UNESCO. Definition of Youth.* 2015.

Stein LD. *The ten basic principles of good parenting.* 2004
How to transition

What’s the plan?
Aims of transition

- Successful move from paediatric to adult care
- Support self management
- Encourage independence
- Support future planning
- Improve clinical markers (lung function, BMI)
- Education
What are the options?

- An abrupt transfer to adult services
- Staying in paediatrics longer than is appropriate
- Following a planned programme of transition

*Department of Health (UK). Transition: getting it right for young people. 2008.*
Making it work

- Transition takes time
- Transition does not stop at the point of transfer, it should continue for a period of time into adult care
- Joint multidisciplinary working (paediatric + adult)
- Good communication

*Department of Health (UK). Transition: getting it right for young people. 2008.*
*NICE guideline (NG43) 2016. Transition from children’s services for young people using health or social care services.*
Potential challenges
- Parents
- Teenagers
- Paediatric teams
- Adult general medicine

Sometimes you need to let things go.
Parents

- Concern about a new place / change
- Loss of control
- Concern about child’s ability to manage independently
- Trust
- Loss of child to adulthood

Teenagers

- Scared of change (but used to transitions)
- Attachment to staff - ‘extended family’ / trusting relationships
- Adult issues – infection, fertility, insurance, education, employment, risk taking behaviour
- Step closer to death

Paediatric team

- Concern about availability of adult CF centres
- Concern about abilities of staff at adult centres
  - USA survey 20% still being followed by paediatrician
- Attachment to families – more than a specialist clinician
- USA survey – criteria for transition:
  - Marriage and pregnancy
  - Precluding transition patient/family resistance

Adult general medicine

- No knowledge, not interested
- Heavy work load – growing population of expensive and demanding patients
- No service provision, local health services reluctant to provide support or resources
- Growing population (75% over next 20 years in Europe)
- No health services money for new centres
  - Physician training programmes in the UK and USA sponsored by CF Trust and CFF – charities

Making it work
Planning

Timing
- Start early – from infancy
- Flexibility to take into account maturity and state of health (although should not be used as an excuse to delay)

Formal
- Plan agreed by both the paediatric and adult team
- Care plan
- Personal folder

Communication
- Between paediatric team, adult team, parents and young adult
- Transition buddy

Support post-transition

RBH transition

Early discussion – annual review

Start seeing alone at consultations

Invitation to pre-transition clinic/transition clinic, transition buddy

Information about taking responsibility, choices, etc.

Transition folder completed by parents, young adult and paediatric team (diagnostic data, life events, demographic data, ‘about me’) – sent to adult team. *Patient held records being designed*
Transition programme

Paediatric and adult teams meet before clinic

Joint clinic – each with opposite colleagues

Discussion with parents and young adult, questions, review current treatment

Tour of ward and other facilities, meet ward staff

If happy, next OPA with same members of the adult team, if not can attend another transition clinic
Transition buddy (July 2017)

- Pre-transition and transition in specific outpatient clinics or on paediatric ward
- At first meeting exchange email addresses
  - patient and transition buddy (exclusive address)
- After clinic send animation links and ask for feedback (cards being designed with QR codes)
- Transition buddy (+ other CNSs) attend paediatric parents evenings

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<th>Comments</th>
<th>Pre-transition</th>
<th>Transition</th>
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<td>Good</td>
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<td>It was so long ago, I can’t remember what was in them</td>
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<td>This is a great job</td>
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<td>Very friendly and relatable</td>
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<tr>
<td>I liked the animation</td>
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<td>2</td>
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<tr>
<td>Very good</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>12</strong></td>
<td><strong>12</strong></td>
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Making it work

- Start early (at diagnosis!)
- Have confidence in your transition preparation
- Positive messages about adult service (good relationship)
- Named person to coordinate – transition buddy
  - Attend meetings with paediatric team
  - Management issues
  - Involve other adult team members where necessary
  - Visit other hospitals/teams
- Transition ready – patient and parents
Making it work

- Privacy and confidentiality
- Mutual respect and honesty
- Acknowledge expert patient
- If in doubt ask
- If not happy say so and why
- Falling out – on going support
- Partnership
- Different contact methods – technology
Making it work

- Before starting university: exam results, future planning, travelling
- Employment issues - who to tell and when?
- Financial issues - benefits
- University- contacts, letters, other centres
- Living with friends - housing, space for meds, fridge space
- Shopping, cooking, prescriptions, feeling unwell
- Parental involvement
- CF is not a priority
Making it work

- Taking charge – medication, treatment?
- Involvement in treatment decisions
- Non-adherence – never perfect, realistic
- Second diagnosis – e.g. CFRD
- Support vs. independence vs. interdependence
- Accept that mistakes/omissions will be made
  - Pre-transition patients and families identify the downside
  - Post-transition describe the benefits

More challenges

- New environment
- New staff
- Changes at home, leaving home
- Changes at school / university
- Perceived new rules – not always correct – rumours
- Growing up and away from parents
- Parents dilemma – where do they fit in?
Coming of age?

- Cystic fibrosis as a chronic condition?
- Maintain health parameters as normal from an early age:
  - lung function, BMI, *Pseudomonas aeruginosa* free
- Plan for a full adulthood, integrated into society, no differentiation from peers
- New issues / emerging challenges: issues of aging, care of the elderly
- Enable independent, active and successful lives throughout adulthood
Conclusions

- Children surviving to adulthood - increasing numbers of adults with CF
- Adult services slow to catch up
- Increasing complexity of care requires MDT with expertise
- Stress free transition (patient, parents, paediatric team, adult team)
- Start of a long term relationship (50+ years??)
- Confidence in new team

Safe  Caring  Effective  Responsive  Well-led