Transition to Adult Care: Ready Steady Go

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Clinical Lead for Transitional Care
About you...

A. Patient/carer
B. Healthcare professional
C. SCN team
D. CCG member
E. CRG member
F. Manager
Transition

• “a purposeful, planned process for adolescents with chronic physical & medical conditions as they move from child-centred to adult orientated health care.

• A process that addresses their
  – Medical needs
  – Psychosocial needs
  – Educational/vocational needs

Blum et al 1993

Transfer is a single event
## Why is transition needed?

<table>
<thead>
<tr>
<th>Disease</th>
<th>Literature References</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>IDDM</td>
<td>Kipps et al 2002</td>
<td>94% attending OPD in paediatric services. 57% attending OPD in adult services at 2 yrs.</td>
</tr>
<tr>
<td>Congenital heart disease</td>
<td>Sommerville 1997</td>
<td>70-80% reach adult life; Mean death 25.4 yrs. 1:5 premature/avoidable.</td>
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<td>Hydrocephalus</td>
<td>Tomlinson et al 1995</td>
<td>FU 100% paediatrics. 40% in adult services. 95 pts; 13/95 died – presumed secondary to shunt.</td>
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<td>Renal</td>
<td>Watson A 2002</td>
<td>20 renal transplants. 8 transplants failed. 7 unexpected.</td>
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Good Transition

• Improved follow-up
• Improved patient & parent satisfaction
• Improved disease control & disease knowledge
• Improved documentation of adolescent issues
• Improved health related quality of life
• Vocational readiness

Transition - what do you think?
When would you consider starting transition

A. 1 year before transfer to adult services
B. 16 yrs
C. 14 yrs
D. 12 yrs
E. 11 yrs
An adult physician needs to be identified before starting transition

A. Yes
B. No
Is transition needed if the young persons care is transferred to the GP?

A. Yes
B. No
Can a young person with learning difficulties undergo transition?

A. Yes
B. No
Does a transition programme need to be disease specific?

A. Yes
B. No
What do young people want

- Start transition early
- Individualised approach
- Honest explanation of adolescent condition and associated health care
- Continuity in health personnel
- Opportunity to see health professional without parents
- Able to express opinions and be involved in decisions
- Address medical, psychosocial, educational/vocational needs
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Ready Steady Go
Ready Steady Go: Literature

- 1998  Bridging the Gap.  Vancouver
- 2003  NSF Stds, Bridging the Gap, Good transition
- 2004  NSF – Core Std 4, RCN Transition Guidelines, Every Child matters
- 2005  You’re welcome (DoH) Transitions: Young Adults with Complex Needs
- 2006  Transition Getting it Right, Youth Matters:Next steps
- 2007  Growing Up Matters, Transition Guide, Your Welcome (DoH)
- 2008  Moving on Well, Tackling the Health of the Teenage Nation
Ready Steady Go: The beginning

• Literature search
• Discussed with other sub-specialities
• Experience from other hospitals - UK, Canada, Australia

• Transition Steering Group
  – Cardiac, nephrology, respiratory, community, diabetes, rheumatology, gastroenterology, haematology, oncology
Ready Steady Go: Transition Programme

• What?
  • A purposeful, planned process for adolescents with chronic physical and medical conditions as they move from child-centred to adult orientated health care.

• Why?
  • Reduce morbidity and mortality
  • Improves vocational success

• Who?
  • Young people >11yrs with chronic condition

• How?
  • Ready Steady Go programme

www.uhs.nhs.uk/readysteadygo
Ready Steady Go: Transition Programme

- Knowledge
- Self advocacy
- Health + lifestyle
- Education/future
- Psychosocial issues
- Transition
Ready Steady Go: What’s involved?
# Ready Steady Go: Transition Plan

## Transition Plan

### Knowledge
1. Describes condition, effects and prognosis
2. Understands medication purpose and effects
3. Understands treatment purpose and effects
4. Knows key team members and their roles

### Self Advocacy
1. Portfolios clinic appointment on their own
2. Knows how to make appointments/other appointments
3. Understanding of confidentiality
4. Order repeat prescriptions
5. Takes some responsibility for medication/other treatment
6. Knows where to get help

### Health and Lifestyle
1. Understands importance of diet/exercise/exacerbation care
2. Understands impact of smoking/alcohol/substance use
3. Understands sexual health risks (pregnancy/STIs)

### Activities of Daily Living
1. Self care: Meal preparation
2. Independent transportability
3. Trips overnight stays away from home
4. Benefits

### Vocational
1. Current and future education/impact of condition on career plans
2. School attendance and performance
3. Work experience and how to access career advice
4. Outside activities and interests
5. Disclosure to school/employer

### Psychosocial
1. Self esteem/self confidence
2. Body/self image
3. Peer relationships/bullying
4. Support networks/family disclosure to friends
5. Coping strategies

### Transition
1. Understands concept of transition
2. Agrees transition plan
3. Attends transition clinic
4. Visits adult unit if appropriate
5. Sets GP independently

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**Ready** Date Signature

**Steady** Date Signature

**Go** Date Signature
Ready Steady Go: Moving through the programme

Ready Steady Go: Each Young person (YP) progresses at their own pace

11-12 yrs
YP and carer
Introduced to
Ready Steady
Go programme

11 – 12 yrs
YP completes
Getting Ready
Issues addressed in
bite sized pieces

14 – 16 yrs
YP completes
Steady for
progress.
Issues addressed
In bite sized pieces

16 – 18 yrs
YP completes
Go. Meets adult
team.
Ideally all issues
addressed prior
to transfer.
On-going issues
highlighted to
adult services.

1st adult clinic
YP +/- carer
Completes Hello
Issues addressed.
by HCP.
Periodically
completed again to
ensure skills
maintained and any
issues addressed

Carer completes parent/carer questionnaire alongside YP questionnaires. Any issues addressed.

YP with learning difficulties completes as much as possible alongside carer who is YP advocate
Ready Steady Go: Making it happen

- **Ready Steady Go (RSG) documentation**
- Information campaign
- Young persons clinic weeks 4 x year
  - Promotes transition
    - MDT, patients and parents
  - Share resources
  - Young person friendly environment
### Ready Steady Go: Snapshot Feedback

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<th>Questions</th>
<th>Responses</th>
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<tr>
<td>The “Transition: moving into adult care” helped patients &amp; family understand why they are starting RSG</td>
<td>93/93 agree</td>
</tr>
<tr>
<td>The questionnaires were easy to understand</td>
<td>93/93 strongly agree/agree</td>
</tr>
<tr>
<td>RSG questionnaires helped focus clinic appt &amp; address difficult issues</td>
<td>90/93 agree</td>
</tr>
<tr>
<td>RSG helps ease the process of transition</td>
<td>93/93 strongly agree/agree</td>
</tr>
<tr>
<td>RSG improved my practice</td>
<td>21/22</td>
</tr>
<tr>
<td>Any questions that would help improve transition?</td>
<td>All – No</td>
</tr>
<tr>
<td>Comments?</td>
<td>Time issues Relevance of some questions especially in patients with learning disabilities</td>
</tr>
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Ready Steady Go: Adoption + Support

• NHS logo
• Sub-speciality groups
  – Diabetes, Cystic fibrosis, Epilepsy, renal…..
• Evelina, Leeds Children’s, Nottingham, BCH…
• Adult engagement with Hello to Adult Services
  – nephrology, diabetes, mental health, GP…..
• SEND
• Public Health England- example of good practice
  http://www.chimat.org.uk/transitions/prof/checklist
Ready Steady Go: Next steps

- Transition website + App
  - Generic + sub-speciality links
- Implementing ‘Hello’
- ‘Hello’ to Children’s services for carers
- Large scale study on long-term outcomes of Ready Steady Go
Transition- what do we think now?
When would you consider starting transition

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Ready Steady Go: Summary

• A generic programme that works across sub-specialities
• Shifting emphasis to empowering the young person
• **RSG** succeeds because:
  – The staged ‘traffic light system’ is appealing, it’s simple to use, easy to implement and has minimal cost
• **RSG-Hello** continuity from paediatrics to adults
**NHS England**

**Generic transition dashboard**

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Questions?

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