Transition after treatment for cancer: Teenagers and Young Adults to Adult follow-up services -

Susan Mehta Lead CNS Late Effects of Cancer UCLH
Effective Transitional Care

“Transition is the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems”

Blum et al, 1993
What does transition mean?

Moving on:
- Chronologically
- Physiologically
- Psychologically
- Services
Why do survivors of teenage cancer need transitional care

- 16,000 children diagnosed with cancer by the age of 15 yrs every year
- Estimated 33,000 childhood cancer survivors in the UK
- Higher premature death rates and increased risk of physical and psychological problems compared with the general population
- Lifelong risk of late effects which may present years or decades later

SIGN 2013
Increased Mortality with time from treatment
Expanding population

- More than 30,000 survivors in UK
- 1 in 750 young adults survivors
- 50% are adults
- Expanding by 1250/yr

Estimated numbers of five-year survivors alive at the end of successive calendar years, by attained age in years. *Great Britain, 1971-2005*

Modified from Charles Stiller ‘Childhood Cancer in Britain’ 2010
When should transition happen?

- No hard-and-fast rule!
- Gradual process
- Starts during early adolescence
- Involves all of us
Key Elements of transitional care identified

- Safe ... independent of parents
- Written information
- Flexible
- Clinical expertise
- Communication
- Use of social networking techniques
- Resources
Teenage and young adult aftercare pathway

Level 1 and 2 supported self management and planned coordinated care pathways

The children and young people pathway - commissioning a solution
Young people encouraged to attend independently

I felt more relaxed on my own

I feel it should have been arranged when I was much younger although I understand it is a new system
The majority of young people preferred both written information and face to face discussion

## Transition in practice

### Treatment Summary

<table>
<thead>
<tr>
<th>Name:</th>
<th>Hosp/NHS No:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of birth:</td>
<td>Sex:</td>
</tr>
<tr>
<td>Age at Diagnosis</td>
<td>Consultant:</td>
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<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Diagnosis date:</th>
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<tbody>
<tr>
<td>Stage/Group:</td>
<td>Treatment end date:</td>
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</table>

Response to treatment (according to disease assessment time points): To be filled in by Acute physicians

<table>
<thead>
<tr>
<th>Trial / Protocol:</th>
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<table>
<thead>
<tr>
<th>Recurrence of Disease</th>
<th>Yes/No</th>
</tr>
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<tbody>
<tr>
<td>Date</td>
<td>Site/s</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Chemotherapy</th>
<th>Yes/No</th>
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<tbody>
<tr>
<td>Drugs with significant potential long-term toxicity received (dose)</td>
<td>Other drugs received</td>
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</table>
Healthy lifestyle choices

Transition in practice

I already eat relatively healthily

Limited sweets and biscuits
Transition in practice

I joined a gym and am walking a lot more.
Transition in practice

Education

Understood about treatment but not late effects. Quite complicated

Employment

I want to progress in my career and I do not want to take time off work
Transition in practice

Drugs, alcohol and smoking

I did smoke and stopped after the appointment
Transition in practice

Sexuality, fertility, and relationships

Will I be able to have children?

I might have HIV infection.

It's not nice talking about your private life in front of your parents.
Psychosocial review

Mental health and psychology

Sometimes I feel suicidal
Good transition...

- Empowers young people to negotiate specialist healthcare, primary care, and self-management with confidence.
- Integrated into the pathway between paediatric and adult services.
- Involves face-to-face discussion and effective information exchange
- Can be nurse led but involves multidisciplinary approach
Case Study: “Kate”

- Age 42 years and attended long-term follow-up 2013
- Referred to long-term follow-up UCLH by GP
- Treated for Left Cervical Hodgkins Disease age 18 years
- Stage 1V Disease
- Relapse Age 20 years
Treatment

- 1989 Mantle radiotherapy to the neck 40Gy in 20 fractions

- 1991 Chemotherapy for 6 months including:
  - Doxorubicin 125mg/m2
  - Vinblastine
  - Etoposide
  - Prednisolone
  - Chlormabucil
  - Procarbazine

- 1991 Splenectomy
Late Effects

• 2006 Bilateral mastectomy and reconstruction for breast cancer
• Palpitations and diagnosed with inappropriate sinus tachycardia (continuing cardiac follow-up)
• Pulmonary fibrosis
• 2012 Left pneumothorax
• Hypothyroidism (thyroxine)
• Arthritis (steroid treatment)
• Osteoporosis
• Migraines (new problem)
• Dysphagia (new problem)
Investigations required

Discussion in an expert multidisciplinary team
MRI spine
DEXA
Vascular imaging
“Completely all alone with all of this”

“I can’t work because I feel so unwell”

“My mother is embarrassed about me”

“My GP does not understand”
Young people who have received effective transitional care will know how to access appropriate services when necessary.

Primary care will be well informed about the individuals risk for developing late effects.
Susan Mehta
Lead Clinical Nurse Specialist Late Effects of Cancer UCLH