Preparing childhood cancer survivors for transition from paediatric to adult services

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THE FOUR STAGES OF ADULTHOOD

- RADULT -
  I CAN DO WHATEVER I WANT!
  NO PARENTS

- SADULT -
  I WISH I COULD DO WHAT I WANTED.

- MADULT -
  KIDS TODAY THINK THEY CAN JUST DO WHATEVER THEY WANT!

- DEADULT -
  THIS IS NOT WHAT I WANTED.

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Background

- What is Transition?
- What we already know……
- Aims of LE follow up
- The survivorship agenda UK
- The Sheffield Experience
- Summary
- DVD clip
Definitions

Late Effects
• Adverse health-related problems that occur months to years after completion of treatment and result from the treatment or disease.

Health (WHO 1948)
• A state of complete physical, mental & social well-being. Not merely the absence of dis~ease

Transition (DoH 2006)
• Transition is the purposeful, planned movement of adolescents and young adults with chronic and medical conditions from child-centred to adult-oriented health care systems.
What we already know

• Cancer treatments are known to be associated with late consequences/late effects.
  – Davies H & Urquhart T 2007 ‘Radiation therapy in children; the long term consequences, CPD in Focus’. SYNERGY Imaging and therapy practice June 24-29

• Health services are facing the challenge of providing care for survivors as they transition from adolescence into adulthood.

• Therefore accurate information about current needs together with a realistic view of the future is essential.
Aims of Late Effects Follow Up

Surveillance / management of medical problems.
Minimise impact on health.

Information and health promotion

Psychosocial Support.
Maximise reintegration into society.
1 of the 10 working principles from the CYP survivorship initiative

• **No 7** All cancer survivors should have pre planned and proactive transition arrangements at all stages of their aftercare
The Sheffield Experience
SCH
Sheffield Childrens Hospital

Principle paediatric Oncology/ Haematology Unit

WPH
Weston Park Hospital

Adult Cancer Hospital with a teenage cancer unit TCT, Part of Sheffield Teaching Hospitals, STH

RHH
Royal Hallamshire Hospital

Large adult hospital, part of the STH NHS Foundation Trust

Regional haematology and bone marrow transplant unit with TYA Haematology ward

TYA and Adult Late Effects Service

Royal Hallamshire Hospital
Preparation for transition clinics

- 5.30 – 7.30 pm
- Refreshments
- Parents/ Carer, TYA, siblings, partners
- x 4 evenings to date
- 54 eligible YP
- 24 attended
- Led by paed team
Multi Disciplinary Approach

- Clinical nurse specialist
- Clic Sargent YP Social Worker
- Consultant paediatric oncologist
- Paed & TYA Psychologist
What happens?

- Welcome and introductions
- May undertake work with a Group of YP and a Group of parents
- General discussion about what transition involves
- Questions and answers - PIZZA
- Message wall & Evaluation
- Visit to MOP in adult trust
Evaluation

• 9-10/10
• Liked the timing of the clinic
• Found the Q&A really helpful
• Useful visiting the new out patient department in the adult trust
• YP discussed other topics relevant to their age group; driving tests, colleges, university
• Exchanged social media
Solid Tumours
5 years post EOT
Brain Tumours
5 yrs post EOT (or joint follow up earlier if required)
Neurooncology Clinic

Leukaemia
3 years post EOT

Transplants
2 years post transplant or joint follow up if required earlier

Referral to Late Effects Clinic:-
(Direct to Tanya Urquhart (TU), Macmillan CNS in Late Effects (Keyworker)).
EOT Summary produced by referring team. (Referral will not be accepted without completed EOT Summary).

Personal EOT Surveillance Plan created/finalised by TU. Referral discussed in LE MDT prior to first appointment and plan made for ongoing follow up.

Nurse Led Clinic for Low Risk patients

Consultant led Clinic for medium / high risk patients
+/-
Endocrine + Late Effects Clinic (monthly). Endocrine + Late Effects + Neurosurgery (Bi monthly)

Age 16 – 18
SCH LE MDT to plan transition
Patient meets with TU to re review Personal EOT Surveillance Plan and discuss transition process (SCH Preparation for Transition Meeting ~2x/year)

Referral to RHH TYA LE MDT
Ongoing follow up in RHH

SHEFFIELD CHILDREN’S NHS FT LATE EFFECTS REFERRAL PATHWAY

WPH TYA MDT refers to RHH
TYA LE MDT
(SCH patients diagnosed age 13 – 16)
Age 16 – 18
SCH LE MDT to plan transition

Patient meets with TU to re review Personal EOT Surveillance Plan and discuss transition process (SCH Preparation for Transition Evening Meeting ~2x/year)

Multidisciplinary

Referral to RHH TYA LE MDT
Ongoing follow up in RHH:-
• Face 2 face consultations, Cons and Nurse Led.
• Telephone follow up clinics

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Age 16 – 18
SCH LE MDT to plan transition

Patient meets with TU to **re review**
Personal EOT Surveillance Plan/
survivorship care plan and discuss transition process

*(SCH Preparation for Transition Evening Meeting ~2x/year)*

**Multidisciplinary**
Age 16 – 18
SCH LE MDT to plan transition

Patient meets with TU to re review Personal EOT Surveillance Plan and discuss transition process
(\textit{SCH Preparation for Transition Evening Meeting} \sim 2x/\text{year})

\textbf{Multidisciplinary}

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Referral to RHH TYA LE MDT
Ongoing follow up in RHH:

Together we care
Referral to RHH TYA LE MDT

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The Sheffield Experience

• Established LE service > 18 yrs

• Improvements to Transition in recent years

• Multidisciplinary approach at **ALL** levels –
  – Cons Paed Oncology
  – Prof Adult Endocrinology
  – Cons Paed Endocrinology
  – Cons Adult Reproductive Medicine
  – Cons Psychiatry
  – Psychology
  – Youth Support Workers
  – Cons Nurse LE
  – Macmillan CNS Paed & TYA LE

• Approx 50 - 60 New Transitions each year
2 Transition TYA LE/ Endo clinics each month, comprising:

- 1st Tues each month – x 4 clinics;
- x 2 Cons Led –
  - x 1 adult endo
- x 1 paed oncologist
- x 2 Nurse Led Clinics
  - x 1 CNS Paed and TYA LE
  - x 1 Consultant nurse LE
- x 1 psychologist
- x 1 psychiatrist
- x 1 cons reproductive medicine
- Haematologists/ BMT spec
- Adult Endo investigation unit

- 3rd Tues each month – x 4 clinics;
- x 2 Cons Led –
  - x 1 adult endo
- x 1 paed endo
- x 2 Nurse Led Clinics
  - x 1 CNS Paed and TYA LE
  - x 1 Consultant nurse LE
- Haematologists/ BMT spec
- Adult Endo investigation unit
What are we trying to achieve?

- Access
- Service Continuum
- Excellence & Innovation
TRANSITION FROM CHILD TO ADULT SERVICES

GOAL - To ensure all young people are adequately assessed and appropriately managed during transition to adult services.

PREFERRED OUTCOME: - Appropriate planning of care for the child/young person and their guardian/next of kin to ensure a smooth transition between Child and Adult Services.

Transition planning for young people with complex health needs or a disability
Good transitional care for survivors of childhood cancer
Transition - In Summary

- Key component of the survivorship journey.
- No national/ international consistency.
- Empower YP to make own health care decisions.
- There is no definitive age for transition, this is driven by the individual needs of each patient.