Supporting children and families with childhood cancer

Joanna Stone
Lead Nurse for Children and Young People
Objectives

To explore areas where GPs have a key role in childhood cancers

Early diagnosis* and referral
Providing on-going support through treatment
Survivorship follow-up
Bereavement follow-up

* Diagnosis will be discussed in Dr Marshall’s session
Referral criteria

**Geographical area**
Referral catchment area with malignancy is South East England, South Thames region. External referrals are accepted where clinically appropriate. 16 POSCU’s in this area.

**Age**
- < 1 year or < 8 kg – patients to GOSH
- 1 – 16 years – referral to paediatric team
- 16 – 24 years – referral to Teenage and Young Adult (TYA)

**Tumour specific exceptions**
- Bone tumours - Stanmore
- Retinoblastoma – The Royal London
South Thames Principle Treatment Centre (PTC)

**Royal Marsden**
- 18 paediatric inpatient beds – chemotherapy / BMT
- 9 TYA inpatient beds
- Day care and outpatient
- Radiotherapy
- Palliative care
- Drug development
- (No paediatric critical care unit)

**St George’s Hospital**
- 4 oncology beds
- POSCU
- Surgery
- PICU

**Kings College Hospital**
- Neurosurgery

Quality of life for survivors of medulloblastoma
Referral to South Thames Cancer Network

- Birth surveillance
- A+E / other hospital department
- Routine / Emergency GP referral
- Child Health
- GP two week rule referral
Referral pathway to The Royal Marsden

Referral to hospital- Paediatric Unit

DIAGNOSIS / SUSPICION OF MALIGNANCY

Clinical assessment
Bloods and imaging as appropriate

After appropriate stabilisation contact Paediatric Oncology Registrar on call at RMH via hospital switchboard.

Consultant Paediatrician to discuss possible diagnosis with family.

If patient unstable may require discussion with South Thames Retrieval Service
Contacting Royal Marsden - 24 hour telephone helpline for patients, families and health care professionals

0208 915 6248
Guidance at Oak Centre for Children and Young People on www.royalmarsden.nhs.uk
SUPPORT DURING TREATMENT
Practical support for families at RM

Facilities for parent to stay with child
Open visiting
On site catering staff 7am – 7pm
Kitchen and laundry facilities for parents
Four charity funded flats in Belmont
Transport service – self referral
Interpreting service
Play specialist team and play facilities
Schoolroom
Support services available

Keyworkers
  CNS leukaemia, neuro, solid tumour, lymphoma, BMT, late effects
CLIC (and other charities)
Psychology
Safeguarding team
CYP Oncology Outreach Nurses
Shared Care Units – direct access up to 6 months
Community Nurse
Rehabilitation team – dietician, physiotherapy, OT, SALT
Pyrexia

**Symptom Assessment**
One temperature of 38°C or above

- **YES**
  - Has patient recently received chemotherapy or is on maintenance therapy?
  - Has maintenance therapy been stopped/reduced due to low count?
  - Does the patient have a CV line?

- **NO**
  - Is the caller worried that the patient is generally unwell?

**YES**
- If the patient has been off treatment for more than 3 months advise GP review if symptomatic

**NO**
- Advise to attend shared care centre immediately

---

**Gentamicin + Tazocin**

**Teicoplanin**

Respond to blood culture results
Fungal workup – CT + antifungals
Bleeding, bruising and anaemia

Review at POSCU for –

- Unexplained bruising, petichael rash, spontaneous nose bleeds > 10 mins, blood present on cleaning teeth
- Pallor, feels cold, is breathless on exertion or tired / lethargic.

*General advice on transfusion:*

Hb < 7 or < 10 for patients receiving radiotherapy
Platelets < 10, < 20 if febrile and < 30 for children with brain tumour
Nausea and vomiting

Symptom assessment

2 hours of nausea/2 vomits in 24 hours

Has the child received chemotherapy in the last 1-3 days?

YES

Ondansetron

Dexamethasone

(short term use)

NO

Cyclizine

Levomepromazine

Has the child received chemotherapy in the last 1-3 days?

YES

Have prescribed anti-emetics been given?

YES

Is patient able to take oral?

NO

Advise to give anti-emetics and phone again if no improvement

To attend POSCU for review

NO

Dexamethasone or could they be at risk of Raised Intracranial Pressure?

YES

Does patient have Brain Tumour or could they be at risk of Raised Intracranial Pressure?

NO

Is there evidence of blurred vision and/or headaches?

YES

To attend POSCU for review

Is there evidence of abdominal pain or distension?

NO
True or false questions
Children receiving chemotherapy should not attend school?

A. True
B. False
Children receiving chemotherapy should follow a special diet?

A. True
B. False
Children on chemotherapy should receive the seasonal influenza vaccine?

A. True
B. False

71% True
29% False
Children receiving chemotherapy should receive prophylactic antibiotics?

A. True

B. False
Infection contact

Schooling
Coughs and colds
Diarrhoea and vomiting
Vaccinations
Food
Mucositis

Symptom assessment

1. Recent chemotherapy consisted of high risk chemotherapeutic agents e.g. Methotrexate, Doxorubicin, Vinblastine
   2. Recently or is still receiving radiotherapy to head and neck region
   3. Decreased ability to tolerate oral fluids

 a) Has medication been prescribed for the treatment of mucositis?
 b) Is fluid intake adequate?

YES

Has medication been administered correctly?

NO

YES

• Advise on use of analgesics and other supportive medicines
• Initiate prescription locally if needed

1. Is patient in acute pain/distress?
  2. Is fluid intake inadequate?

To attend POSCU immediately

Maintain oral hygiene

Soft toothbrush and regular toothpaste

Encourage oral fluid intake

Care of skin in perianal region

Prompt management of constipation
Immunisation

- Patient on treatment OR Within 6 months of completing treatment: YES
  - NO immunisation – except for annual influenza vaccine in autumn or pneumococcus as advised

- Patient more than 6 months off treatment: YES
  - Discuss at next clinic visit and send vaccination guidelines to GP
Palliative care and Bereavement follow up
Palliative care

Palliative care team –
Palliative care consultant, CNS team for palliative care (CYPOONs)

Palliative care MDT
Meeting arranged at GP practice
To include – GP, palliative care team, community nursing team, hospice, family invited

Discussion –
Community support
Symptom care box (3 days prescription) - Prescribing support
Individualised symptom management guidelines
Child death review – medical visit every two weeks
Local support in area for families
Incident
How many deaths from malignancy are there in the South East each year?

A. 5 – 10 / year
B. 30 – 40 / year
C. 60 – 70 / year
D. 100 / year
GP support

GP central to on-going support for families

Asked by RM team to support
- Child death review – to visit every minimum of two weeks
- Assessment of acute symptoms, e.g. chest infection, urinary retention
- Provision of ongoing prescriptions for symptom management
- Authorisation of death for certificate
PATCH service

Paediatric Patient Advice by Telephone for Care at Home, Hospice or Hospital

Supports services close to children’s home, local hospital or children’s hospice

Telephone service available out of hours, seven days a week to families and professionals
Bereavement

Key contact person identified for each family post death (voluntary)
Telephone contact following the death

Funerals – RM policy maximum of 4 staff to attend funeral
Telephone contact 6-8 weeks post death

Post-death internal MDT and put on EPR to reflect ongoing involvement from RM or not

Telephone contact 3-6 monthly for 2 years

Psychosocial team available for RM and community professionals
Bereavement

CLIC-Sargent Social Workers/Psychologists

Bereavement group – (closed) annually

Family bereavement days

Annual Christmas service – Forget Me Not Trust (open invitation)

1st Anniversary flowers (funded by Forget Me Not Trust)
SURVIVORSHIP FOLLOW UP
When is a child most likely to experience side effects from treatment for malignancy?

A. Six months after treatment
B. Twelve months after treatment
C. Five years after treatment
D. Ten years after treatment
Severity of late effects:
As a general rule, which of the following children would be at most risk of developing late effects from treatment?

A. Child < 10 years at the time of treatment receiving standard doses of chemotherapy
B. Child < 10 years at the time of treatment receiving radiotherapy
C. Child > 10 years at the time of treatment receiving standard dose chemotherapy
D. Child > 10 years at the time of treatment receiving radiotherapy
Late effects of treatment

Increase in survival has resulted in increased focus on long term side effects

Important factors
1. Time from treatment
2. Regular follow up is essential
3. Good health habits are important for survivors
What is the incidence of secondary malignancy in children treated for leukaemia?

A. 1%
B. 5%
C. 10%
D. 25%
Treatment effects

Secondary malignancy
Neuropsychology
Vision
Auditory
Dental
Endocrine
Cardiac
Respiratory (*bleomycin*, infection)
Renal
Urinary tract
Bone density
Long term follow up service at RM

Consultant and CNS team

Treatment summary

Details treatment received
Identifies potential complications
Identifies screening required

Summary sent to GP and copy of patient encouraging to take the summary to all health care appointments.
Paediatric support

Follow up appointment at RM for all patients until the age of 18 years – monitors late effects and provide advice on healthy lifestyle

Telephone support service to patients, families and health care professionals
Young adult support

Patients who have received intensive treatment, including BMT and radiotherapy:

Referred to the adult services at Brighton and UCLH

Patients who have received standard dose chemotherapy:

Supported self management from 18 years – encouraged to attend GP annually
(poor patient compliance)
**Final points**

Patients, families and health care professionals are encouraged to call the **24 hour helpline on 0208 915 6248** for any concerns or oncology related issues.

Multi-disciplinary team recognises importance of supporting children and family in local area wherever possible and clinically appropriate.

Advances in treatment have resulted in raised awareness of the late effects of treatment for children cancer survivors.