

**LONG TERM FOLLOW UP**

- All survivors of childhood cancer should be actively followed up for life.
- At the end of a course of cancer treatment, patients, their carers and general practitioners should be given a summary of the treatment and a list of signs of late effects to look out for.
- Each patient should have access to an appropriate designated key worker to coordinate care.

With appropriate training, specialist nurses can make a significant contribution to the care of these patients.

**Levels of follow up**

Level	Treatment	Follow up method	Frequency
1	<ul style="list-style-type: none"> <li>■ surgery alone</li> <li>■ low risk chemotherapy</li> </ul>	postal or telephone	1-2 years
2	<ul style="list-style-type: none"> <li>■ chemotherapy</li> <li>■ low dose cranial irradiation ≤ 24 Gy</li> </ul>	nurse or primary care led (using protocols)	1-2 years
3	<ul style="list-style-type: none"> <li>■ radiotherapy, except low dose cranial irradiation</li> <li>■ megatherapy</li> </ul>	medically supervised late effects clinic	annual

**PATIENTS AND FAMILIES**

Patients and their families should be fully informed of the likely consequences of different treatment options as well as of the necessity for vigilance over possible long term side effects. They should be reassured that if signs are picked up early, many potential problems can be avoided and that it is essential for them to attend regular review appointments.

**SOURCES OF INFORMATION AND OTHER SUPPORT**

**Cancer and Leukaemia in Childhood (CLIC)**

CLIC, Abbey Wood Business Park  
 Filton, Bristol, BS34 7JU  
 Tel: 0845 301 0031, Fax: 0117 311 2649  
 Email: clic@clic.org.uk  
 Website: www.clic.uk.com

**Children with Cancer and Leukaemia Advice and Support for Parents (CCLASP)**

Suite 5, Leith Walk Business Centre,  
 108/152 Leith Walk, Edinburgh, EH6 5DT  
 Tel: 0131 467 7420, Fax: 0131 467 7421  
 Email: cclasp@hotmail.com

**SOURCES OF INFORMATION AND OTHER SUPPORT (Contd.)**

**Macmillan CancerLine**

Macmillan Cancer Relief,  
 89 Albert Embankment, London, SE1 7UQ  
 Freephone (Mon - Fri 9am - 6pm): 0808 808 2020  
 Textphone: 0808 808 0121  
 Email: cancerline@macmillan.org.uk  
 Website: www.macmillan.org.uk

**Maggie's Centres Scotland**

The Stables, Western General Hospital,  
 Crewe Road South, Edinburgh, EH4 2XU  
 Tel: 0131 537 3131, Fax: 0131 537 3130  
 Email: maggies.centre@ed.ac.uk  
 Website: www.maggies.ed.ac.uk

**National Alliance of Childhood Cancer Parent Organisations (NACCPO)**

3 Churchview Close, Bestwood Country Park,  
 Arnold, Nottingham, NG5 9QP  
 Tel: 0115 9673106  
 Website: www.naccpo.org

**Sargent Cancer Care For Children (Scotland)**

5th Floor, Mercantile Chambers,  
 53 Bothwell Street, Glasgow, G2 6TS  
 Tel: 0141 572 5700, Fax: 0141 572 5701  
 Email: glasgow@sargent.org

**Tak Tent Cancer Support Scotland**

Flat 5, 30 Shelley Court,  
 Gartnavel Complex, Glasgow, G12 0YN  
 Tel: 0141 211 0122, Fax: 0141 211 3988  
 Email: tak.tent@care4free.net  
 Website: www.taktent.org.uk

**Teenage Cancer Trust**

38 Warren Street London W1T 6AE  
 Tel: 0207 387 1000, Fax: 0207 387 6000  
 Email: tct@teencancer.bdx.co.uk  
 Website: www.teencancer.org

**The United Kingdom Children's Cancer Study Group (UKCCSG)**

Aims to improve the management of children with cancer and to advance the knowledge and study of childhood malignancy.  
 Website: www.ukccsg.org



**SIGN Executive**  
 Royal College of Physicians  
 9 Queen Street, Edinburgh EH2 1JQ



**Long term follow up of survivors of childhood cancer Quick Reference Guide**



## LONG TERM FOLLOW UP OF SURVIVORS OF CHILDHOOD CANCER

This Quick Reference Guide provides a summary of the main recommendations in the SIGN guideline on the long term follow up of survivors of childhood cancer. The guideline is applicable to all young people who have survived cancer, including brain tumours. The guideline is aimed at primary care staff who follow up cancer survivors as well as secondary care and late effects clinic staff who manage the long term care of this group of patients. This guideline contains recommendations for effective practice based on current evidence.

The recommendations are graded **A B C D** to indicate the strength of the supporting evidence.

Good practice points  are provided where the guideline development group wishes to highlight specific aspects of accepted clinical practice.

Details of the evidence supporting these recommendations can be found in the full guideline, available on the SIGN website: [www.sign.ac.uk](http://www.sign.ac.uk)

### GROWTH PROBLEMS

**B** All children who have survived childhood cancer should have their height measured regularly until they reach final adult height.

**B** Children with craniopharyngioma should be tested at presentation for growth and other pituitary hormone deficiencies, and at regular intervals thereafter.

**C** Children with impaired growth velocity should be referred to a paediatric endocrinologist for growth hormone level measurement.

**B** Prepubertal girls receiving cranial radiotherapy should be closely monitored for clinical signs of precocious puberty.

Growth assessment requires integration of information including height measurements, bone age and puberty staging, all of which should be plotted onto growth charts.

### Obesity

**B** Regular growth monitoring should include evaluation of body mass index and be related to growth charts.

Advice on healthy eating and exercise should be given early and reinforced regularly.

### GROWTH PROBLEMS (CONTINUED)

#### Treatment with growth hormone

**B** On confirmation of growth hormone deficiency, growth hormone replacement therapy is indicated. For children with craniopharyngioma, the need for growth hormone replacement may be from presentation.

**C** If the cause of growth impairment is unclear, a trial of growth hormone treatment may be appropriate.

**B** Survivors of childhood cancer should be informed that current evidence indicates there is no increased risk of cancer recurrence from growth hormone replacement therapy.

#### Dental and facial problems

**B** Children undergoing cancer treatment, and their parents/carers, should be advised about the possible effects on orofacial and dental development. Specialist paediatric dentists should have a role in the care of these children.

Children undergoing cancer treatment should see a specialist in paediatric dentistry and be advised to attend for routine dental monitoring as recommended for every child.

### PROBLEMS WITH PUBERTY AND REPRODUCTION

#### Male puberty and fertility

Assessment of male pubertal development and fertility should include:

- assessment of testicular volume using the Prader orchidometer
- Tanner staging of secondary sexual development
- measurement of serum FSH, LH, testosterone, inhibin B
- semen analysis.

Men who have evidence of impaired fertility should be referred for specialist assessment as they could benefit from assisted reproductive technology (ART).

Fertility counselling should be provided to survivors of childhood cancer.

Cryopreservation of semen should be offered for young male patients whose cancer therapy will include potentially gonadotoxic treatments.

#### Female puberty and fertility

**C** Girls treated with cranial irradiation should have their pubertal status assessed three to four times a year from the end of treatment as part of a routine clinical assessment.

**C** Women who have evidence of impaired fertility should be referred for specialist assessment as they could benefit from assisted reproductive technology.

### CARDIAC PROBLEMS

**C** Healthcare professionals should be aware that:

- effective doses of anthracyclines for the treatment of childhood cancer may cause congestive cardiac failure later in life.
- mediastinal irradiation over 30 Gy is a risk factor for cardiac disease in later life and monitoring is necessary.

These potential problems should be assessed during regular review.

Children with satisfactory left ventricular function on simple echocardiographic measures who have received modest cumulative anthracycline doses (<250 mg/m<sup>2</sup>) may benefit from three-yearly echocardiogram surveillance.

Survivors of childhood cancer who are pregnant, considering becoming pregnant, or wishing to take part in competitive sports should have a detailed cardiological assessment.

Survivors of childhood cancer should be advised from a young age to:

- follow a healthy diet
- take regular exercise
- avoid taking up smoking or to aim towards smoking cessation.

### THYROID DYSFUNCTION

**B** Survivors of childhood cancer who received radiotherapy to the neck, spine or brain should have thyroid function checked after completion of treatment and regularly thereafter. Survivors are likely to require lifetime surveillance.

Survivors should be advised of the risk of thyroid cancer and to seek urgent medical attention if they notice palpable neck masses

- Annual thyroid function tests are recommended for survivors at risk of thyroid dysfunction.

Thyroid hormone replacement therapy is generally safe and effective. Thyroxin may need to be introduced gradually in people with potential cardiac dysfunction (eg in patients who have received anthracycline).

### COGNITIVE AND PSYCHOSOCIAL OUTCOMES

**D** Healthcare and education professionals should be aware that the treatment of childhood cancer may have an impact on neurological, educational and social function in later life, particularly if irradiation of the brain occurs at a young age.

**D** Regular review for such a deficit should be part of normal follow up.

**D** If a problem is suspected, the patient should be referred for a cognitive or other appropriate assessment.

Children with cancer who are due to receive cranial irradiation should undergo a cognitive assessment with a standard measure (eg an abbreviated version of the Wechsler Intelligence Scale for Children) at the start of treatment. The assessment should be repeated annually.