

## Academic Report

### **Clinical Department Visit Grant** **Memorial Sloan-Kettering Cancer Centre – Survivorship programme** **December 2009**

#### **Grant Awarded to: Dr Maralyn Druce April 2009**

One in 1000 young adults is a survivor of childhood cancer. Today there are over 15,000 survivors of childhood cancer in the UK compared to 1,400 in 1971 (1). NICE guidance highlights the need for separate late effects clinics and the importance of age-appropriate services for adult survivors of childhood cancers (2). In the UK at present, the number of childhood cancer survivors is increasing by 1200 each year (2) and the accepted view at present is that they should be followed up for life (long-term natural history not known).

There are important points of interface between endocrinology and cancer services. In addition to the occurrence of malignancy within endocrine organs (adrenal cancer, thyroid cancer etc), these include:

#### 1) Acute effects of cancer therapies and 'persistent toxicities'

Some of these are well described, for example the use of high doses of prednisolone as part of chemotherapy regimes leading to exogenous suppression of the hypothalamo-pituitary-adrenal axis. However, many such effects are being newly recognised with the introduction of novel agents, such as destructive thyroiditis or exacerbation of Graves' disease due to sunitinib treatment. A number of similar reactions may be as yet unrecognised

#### 2) Late effects on the endocrine system after treatment of childhood cancers

Many late effects on the endocrine organs are described following treatment for childhood cancer (3). These are diverse and include premature ovarian failure due to alkylating agents, pituitary dysfunction consequent on cranial irradiation or iron overload due to multiple blood transfusions and an increased risk of thyroid dysfunction and carcinoma following head and neck radiotherapy.

#### 3) Late effects on the endocrine system after treatment of cancers in adulthood

In addition to children surviving cancer for longer, adults treated for cancers enjoy increased survival rates and longer lives. Consequently the endocrine effects of treatments are being increasingly recognised. The case for robust screening and surveillance is growing and is further compounded by the introduction of new agents and regimes for which the long-term effects are uncertain. Subgroups of patients are clearly identifiable at particular risk of specific sequelae (4-6).

Our unit has a large referral practice for malignant disease in childhood including solid tumours and haematological malignancies. A substantial proportion of these patients have endocrinopathy consequent upon the disease and/or its treatment. Currently service provision is non-uniform and a new strategy is required for identification and management of such patients as is a framework for clinical research in this area.

A leading centre for the provision of services and development of research programmes involving survivors of cancer is the unit at Memorial Sloan-Kettering in New York, USA.

They run three programs:

- a) Paediatric Long-term follow-up
- b) Adult Long-term follow-up for high risk adult survivors of pediatric and young adult cancer (Hodgkin's, BMT, brain tumour, sarcoma)
- c) Survivors of adult cancers

The department have participated in the publication of an excellent set of guidance notes (7) which complement the available UK guidelines published by SIGN and the UK Childhood Cancer Survivors Group (CCSG).

St Bartholomew's Hospital has available a weekly clinic for survivors of childhood cancer, run jointly by a paediatric oncologist and an adult endocrinologist. Inspired by the spectrum of endocrine disorders seen in some of these patients together with an array of complex medical needs, I arranged a clinical department visit under the supervision of Dr Kevin Oeffinger who leads the adult 'survivorship' programme at Memorial Sloane-Kettering Cancer Centre in New York. The aims of the visit were broad, to include experience of clinical aspects of care, an overview of the organisation and development of the service and an insight into the associated research strategy.

The visit comprised a number of elements including:

- An overview of the institution
- An insight into the organisation of services
- Meetings with the lead nurse practitioners to discuss service planning and developments
- Participation in the pre-clinic assessment of late effects risk for individual patients treated for cancer in childhood and the development of management and surveillance plans for these individuals
- Participation in the new patient and follow-up clinics in the survivorship programme for individuals treated for cancer in childhood, both with the attending physicians and with the specialist nurse practitioners
- Participation in nurse-practitioner-led follow-up clinics for patients treated for cancers of various types in adulthood and insight into protocol development for these clinics
- Discussion of key clinical endocrine dilemmas and unanswered questions in this group of patients with Dr Charles Sklar (paediatric endocrinologist and lead clinician for the programme for survivors of cancer in childhood)
- Discussion of potential research opportunities and ways to access data via existing large cohorts

The rationale for the Sloan-Kettering survivorship programme is based on clinical findings from good quality epidemiological research both in the USA and UK. However the programme has been developed on the background of the current model for US healthcare. This lacks a culture in which individuals receive care from a general or primary care physician. A number of US primary care physicians have also expressed either reluctance or lack of confidence in managing ongoing care for these complex patients. A practical model of follow-up to stratify risks of recurrence, persistent toxicity and potential late effects has evolved in order to enable oncology services to maintain throughput of new acute referrals. It has been helpful to analyse this model of care and to consider which aspects might be applicable to UK practice. The relatively high incidence of endocrinopathy in these patients makes it important to understand how endocrinologists might support, participate or even coordinate such a service in the UK. Participation in the clinics has provided a valuable complementary experience to that achieved within our own department and in addition provided some time to discuss and consider some of the clinical questions that in due course could be addressed by clinical research projects initiated and run in the UK.

## Reference List

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