Every day in the UK, six teenagers are diagnosed with cancer, and there has been an increase in certain types of cancer among teenagers and young adults in the last 30 years.

The Teenage Cancer Trust Children and Young People’s Cancer Unit at UCLH is the primary treatment centre for teenage cancer within London and the South East. We offer specialist care for a large number of children and young people diagnosed with a number of different cancers and blood disorders. We provide tertiary and specialist care to a wide area covering both London and many parts of South East England, with about 150 new patients referred each year. Seventy per cent of teenagers from Greater London diagnosed with cancer are treated here.

As the largest Teenage Cancer Trust unit in the country and a Peer-reviewed centre, we are able to deliver exceptional care according to NICE Improving Outcomes Guidance for Children and Young People with Cancer. Together with Great Ormond Street Hospital for Children NHS Trust (GOSH), we operate as a unified cancer centre to form the largest paediatric and adolescent oncology centre in Europe. This alliance allows for the development of unified treatment protocols and for seamless transition of patients from GOSH to UCLH around their thirteenth birthday. Thereafter there is close liaison between consultants, and regular shared multidisciplinary meetings.

The unique strengths of the service are its mix of specialist expertise, state-of-the-art facilities and a modern, age-appropriate care environment. This booklet highlights some of the key features and benefits of the service, and explains the referral options available to clinicians.
Teenage Cancer Trust’s top priority is building units in NHS hospitals specifically for teenagers with cancer. As well as superior medical facilities, these units have well-equipped day rooms, kitchens and relaxation rooms where teenagers can feel at home or have friends and family to visit. Importantly, the units provide an environment where teenagers can meet others in a similar situation, build friendships and develop ways of coping with their disease.

Teenage Cancer Trust also funds several initiatives including:

- the International Conference on Teenage and Young Adult Cancer Medicine
- the world's first Professor of Teenage and Young Adult Cancer Medicine
- the Teenage Cancer Trust Support Network, providing one-on-one counselling and group meetings for ex-patients, family and friends (for more information, see page 9)
- an annual conference, Find Your Sense of Tumour, for 350 cancer-affected teenagers and young adults.

At UCLH, Teenage Cancer Trust funds a nurse consultant post, to ensure the delivery of expert specialist care to young people and their families, develop research and deliver professional education and support.

UCLH has been designated the top-performing NHS trust by the Dr Foster Hospital Guide. This is the second time in the last decade that we have been chosen as the top hospital in the NHS. The trust received the best score in 13 quality indicators, including mortality rates and safety practice. The award reinforces our recent Care Quality Commission ‘double excellent’ score.

Alongside this, UCL was recently ranked as the fourth best university in the world by *The Times Higher Education Supplement*. This confirms UCL’s status as a centre for world-class research.
The Unit provides care and treatment for children and young people with many cancer types, including:

- acute lymphoblastic leukaemia
- acute myeloid leukaemia
- Ewing’s sarcoma
- germ cell tumours
- Hodgkin’s disease
- Non-Hodgkin’s lymphoma
- osteosarcoma
- tumours of the central nervous system.

The Young People’s Haematology Service specialises in the diagnosis and management of both malignant and non-malignant haematological diseases. We have also developed an adolescent bone marrow transplantation service which carries out both myeloblastic and low intensity protocols, as well as having a specialist interest in umbilical cord transplants and the development of alternative stem cell sources. The transplant service is well integrated within the adult transplant service and is now fully accredited by JACIE.1

Transplants are carried out for acute leukaemia, lymphoma (Hodgkin’s and Non-Hodgkin’s lymphoma) and non-malignant conditions such as aplastic anaemia and myelodysplasia. UCLH is unique in being able to provide all these services on one unit.

The Children and Young People’s Oncology Service offers treatment for the full range of tumours common in these age groups and is a supra-regional referral centre for sarcomas in patients of all ages. We are also a regional radiotherapy centre for children, providing radioisotope treatment. We are one of two national centres to offer MIBG therapy for neuroblastoma patients.

The clinical service is complemented by exceptional clinical and translational research within UCL and UCLH with research strengths in a number of areas including bone sarcomas, haematology and bone marrow transplantation, reflecting its position as the site of one of only five National Institute for Health Research Comprehensive Biomedical Research Centres. The opening of a new Institute of Cancer Biology on the campus has further strengthened the research and collaborative infrastructure and allows for greater opportunities in translational research.

1 The Joint Accreditation Committee – ISCT & EBMT (JACIE) promotes high-quality patient care and laboratory performance in haematopoietic stem cell collection, processing and transplantation centres, through an internationally recognised system of accreditation. The Committee was founded by the European Group for Blood and Marrow Transplantation (EBMT) and the International Society for Cellular Therapy (ISCT), the two leading scientific organisations involved with HSC transplantation in Europe.
The 18-bed state-of-the-art ward, funded by Teenage Cancer Trust, has been built with all the equipment a teenager will need to make their stay in hospital as comfortable as possible. Facilities include a plasma TV in each room, internet access, a webcam so patients can stay in touch with friends and family at home, digital lighting so patients can control their surroundings, and a social area where patients can interact with their peers.

Young people with a serious illness are highly dependent on their family for support. Because teenagers with cancer often require prolonged inpatient stays, the ward accommodates a single parent/carer to stay: however hotel accommodation for families is available on a needs-led basis, funded by leading children’s cancer charity CLIC Sargent.

From September 2010 Paul’s House, funded by CLIC Sargent, will extend this facility and offer further self-catering accommodation for patients’ families, in a friendly and welcoming environment. Patients who are well enough will also be able to stay at Paul’s House, increasing the options for ambulatory care.

UCLH is committed to the building of a new state-of-the-art cancer centre, due to be completed in 2012. This centre will provide outpatient and daycare facilities for all cancer patients aged 13 and older. It will provide holistic support in an environment built for cancer care.

The new centre will allow for the extension of initiatives such as ambulatory care, allowing more patients to be treated without an inpatient bed. There will be a floor dedicated to care of the CYPcs patients, which has been designed in conjunction with Teenage Cancer Trust.
Adolescence is a time of enormous change physically, psychologically and socially. Dealing with serious illness at this time of life is complex, requiring the support of an expert multidisciplinary team (MDT). The MDT includes:

- doctors
- nurses and clinical nurse specialists
- teachers
- psychological services
- physiotherapists
- pharmacists
- occupational therapists
- activity coordinators
- dieticians
- complementary therapists
- social workers.

The multidisciplinary team meets weekly to ensure regular communication between team members, and to support a holistic approach to patient care.

This section provides an overview of each of these roles.

**CONSULTANTS**

Our experienced consultants within adolescent haematology and oncology lead on clinical treatment and cover a range of specialisms:

**Adolescent Haematology Service**

**Dr Rachel Hough**
Consultant Haematologist (clinical lead)
*Specialist interests: acute lymphoblastic leukaemia, bone marrow transplant*

**Dr Stephen Daw**
Consultant Paediatric Oncologist
*Specialist interest: lymphoma*

**Dr Victoria Grandage**
Consultant Haematologist
*Specialist interests: acute myeloid leukaemia, non-malignant haematology and late effects*

**Paediatric/Adolescent Oncology Service**

**Dr Jeremy Whelan**
Consultant Medical Oncologist
*Specialist interest: bone and soft tissue sarcomas*

**Dr Sandra Strauss**
Consultant medical oncologist
*Specialist interest: adolescent and adult sarcomas*

**Dr Maria Michelagnoli**
Consultant Paediatric Oncologist
*Specialist interest: paediatric and adolescent sarcomas*

**Dr Sara Stoneham**
Consultant Paediatric Oncologist
*Specialist interest: germ cell tumours*

**Dr Ananth Shankar**
Consultant Paediatric Oncologist
*Specialist interest: neuro-oncology*

**Dr Mark Gaze**
Consultant Clinical Oncologist
*Specialist interest: paediatric and adolescent radiotherapy*

**Dr Yenching Chang**
Consultant Clinical Oncologist
*Specialist interest: paediatric and adolescent radiotherapy*

**Nurse Consultant**
(funded by Teenage Cancer Trust)
Vikky Riley

“We believe that the Unit’s superior medical facilities are likely to lead to an increase in survival rates”

Sir Robert Naylor, Chief Executive, UCLH
NURSING
Nursing forms the core of daily care for each young person in the unit. A clinical nurse specialist (CNS) is allocated to every patient at diagnosis or referral and provides ongoing support throughout the patient journey. The CNS provides information and emotional support, and acts as the link between UCLH and the local hospital and community, as well as with the patient's school or college.

LEARNING SUPPORT
Education is always a concern when a young person is away from school for a prolonged period. A teacher attached to the Unit coordinates study with the patient's school, and can arrange for patients to sit exams or undertake home study as necessary. Together with the clinical nurse specialist, the teacher can also help with the transition back into school life following treatment.

PSYCHOLOGICAL SERVICES
Admission to hospital with the diagnosis of a serious illness can be a confusing and distressing experience for a young person. A member of the child and adolescent psychological services team is available to work alongside other members of the MDT, and with teenagers and their parents, to help understand the issues raised for them by their illness and its treatment, and to build their mental resilience. Support is provided before, during and after treatment, in response to patients’ needs and requests.

PHYSIOTHERAPY
Both cancer and its treatment can affect a patient physically and interfere with their mobility and independence. A physiotherapist will assess each patient and design an individualised training programme, self-directed and/or supervised, to improve muscle strength and stamina. Working alongside an occupational therapist, our physiotherapist aims to enable each individual to reach the maximum possible level of function and independence.

PHARMACY
Chemotherapy and medicines play an important role in the treatment of many childhood and adolescent cancers. Our pharmacist visits the ward on a daily basis to ensure that the chemotherapy is prescribed, validated and ordered in a timely fashion. Other medicines are ordered as required. On discharge each patient is supplied with their own medicines for home use until their next admission is due.

OCCUPATIONAL THERAPY
Our occupational therapists aim to improve patients’ quality of life by a mixture of group and individual work around personal care, functional and psycho-social skills. These aim to maximize young people’s ability to adapt to changes in their lifestyle or physical condition brought on by their illness, and to build their confidence and self-esteem.
ACTIVITY COORDINATORS

Activity coordinators provide an essential role in planning and implementing recreational activities. Their role is to enable a young person to cope better with their stay in hospital by offering them choice and control, and building self-esteem. These activities are designed to reduce stress and anxiety and stimulate creativity and enjoyment. They help prepare young people for treatment and make it appear less intimidating.

The well-equipped activity room also provides a valuable space to meet other teenagers undergoing similar treatment and plays a vital role in facilitating peer support. One of the two activity coordinators on the Unit is funded by Teenage Cancer Trust.

NUTRITIONAL SUPPORT

Nutritional support in childhood and adolescent cancer is an important part of patient care, as treatment is often intensive and can cause sickness and loss of appetite, leading to weight loss. Our dietician assesses nutritional needs and advises on how best these can be met.

COMPLEMENTARY THERAPISTS

The UCLH Complementary Therapy Team offers a range of treatments to young people within the unit, including aromatherapy, reflexology and reiki. Benefits reported by patients include pain reduction, relaxation, increased energy and a reduction in the side effects felt from other aspects of treatment.

SOCIAL CARE

The CLIC Sargent Social Care Team at UCLH provides a specialist social work service for young people aged 24 and under with cancer, and their families. They act as a professional liaison service, supporting communication between the patient’s family and the medical and nursing staff involved in a patient’s care both at UCLH and externally. As part of this, the team provides financial advice and assistance including support applying for state benefits and access to CLIC Sargent care grants, along with other financial benefits. Counselling and bereavement support is also offered.
PARTNERSHIP WORKING AND SUPPORT

STUDY DAYS FOR SHARED CARE TEAMS
We run twice-yearly education days with Great Ormond Street for all members of the Paediatric Oncology Shared Care Unit (POSCU) and community teams, together with a number of seminars designed to facilitate communication and sharing of information between the paediatric treatment centre and shared care teams.

SUPPORT NETWORK
A diagnosis of cancer can be devastating and brings unique challenges for both the young person with cancer and their relatives. An integral part of our service is the Family Support Network that is hosted at UCLH and funded by Teenage Cancer Trust. Historically patients and relatives have identified as highly valuable the support and benefits from being in an environment where they have contact with other young people and relatives going through a similar journey.

However, at times such as the end of treatment, access to support may decrease. To bridge this perceived gap The Family Support Network was established as a nurse-led initiative. The network aims to support young people with cancer aged between 13 and 24 years, and their families, throughout their treatment, but focusing on support at the end of treatment. We also believe the needs of the whole family have to be recognised to better support children and young people.

Every two months we hold an all-day social support day in London. This provides the opportunity for patients and their families to share experiences and gain support from one another, with support and facilitation from health care professionals. Under the umbrella of the network, we also hold bi-monthly bereavement evenings for parents and siblings; this support is recognised as being as important as that provided during any other stage in the cancer journey.

“You become part of a large extended family... it is supportive and gets you through the hardest times”
Sue, a mum

Teenagers on the Unit can socialise and eat together
Typically, patients are referred to us following diagnosis, but can be referred at any time after a clinical assessment or case review.

Please contact:
Children and Young People’s Cancer Service
UCLH Referrals Centre
University College London Hospitals
Ground Floor North, 250 Euston Road
London NW1 2PG

Phone 0845 155 5000
Fax 020 7380 9055

For outpatient referrals contact the relevant consultant via their secretary:
Ext 9950 for Dr Daw, Dr Michelagnoli, Dr Stoneham and Dr Shankar
Ext 5827 for Dr Hough and Dr Grandage
Ext 9346 for Dr Whelan and Dr Strauss

For urgent referrals please contact the relevant registrar via the switchboard:
Haematology Bp 2062
Oncology Bp 5331
Sarcoma Bp 2187

All the consultants can be contacted via the switchboard for case discussion.

Ward contact details:
T11 North 020 7380 9368
T12 North 020 7691 5788
Daycare ext. 71180
Shared care coordinator: Connie Payne
020 7691 5766; Ext 71214
FURTHER INFORMATION

Teenagers and Young Adults with Cancer  
www.tyac.org.uk

Teenagers and Young Adults with Cancer (TYAC) is a membership organisation which helps all professionals involved in the care of young people with cancer.

Children’s Cancer and Leukaemia Group  
www.cclg.org.uk

The Children’s Cancer and Leukaemia Group is a national professional body responsible for the organisation of the treatment and management of children with cancer in the UK.

Teenage Cancer Trust  
www.teenagecancertrust.org

Teenage Cancer Trust funds and equips the building of specialist units in NHS hospitals, and encourages information exchange and the sharing of best practice among medical professionals working in the field of adolescent cancer. For more details of the Trust’s work, see page 3.

CLIC Sargent  
www.clicsargent.org.uk

CLIC Sargent provides a wide range of services and funds care professionals to support children and young people with cancer and their families.