

Teenage and Young Adult (TYA) Service Newsletter

Hello from Leeds!

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Welcome to the first edition of the Teenage and Young Adult Service Newsletter

The purpose of these newsletters are to keep you informed and updated on all that's happening here at the Principal Treatment Centre

(PTC), developments

around the wider TYA service and other relevant information around TYA cancer care. We hope that you find it useful and informative and would welcome any ideas for future issues.



The TYA Specialist Team

Sue Morgan, MBE, Teenage Cancer Trust Nurse Consultant

Dr Dan Stark, Consultant in Medical and TYA Oncology

Dr Bob Phillips, Paediatric Oncologist

Dr Simone Wilkins, Paediatric Oncologist

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Elaine Salvage-Jeans, Macmillan Social Worker

Nicky Tschernitz, TYA Psychologist

Karen Shimmon, Macmillan TYA Psychologist

Cat Carroll, Teenage Cancer Trust Youth Support Co-ordinator

Carrie Pointer, Teenage Cancer Trust Youth Support Co-ordinator

Karen Thomas, Emma Maltby Trust Learning Mentor

Kirsty Faircliffe, TYA MDT Co-ordinator

The Teenage and Young Adult Service And why do we need it?

Cancer is the leading natural cause of death in young adults up to the age of 24.

6 TYA's per day are diagnosed with cancer. 2200 TYA's a year die from cancer and in the last 30 years the numbers of teenagers and young adults with cancer has increased by 50% so that there are now more teenagers with cancer than there are children with cancer. The needs of Teenagers and Young Adults are quite unique.. Adolescence represents a time of great change, both physically and psychosocially. A time when these young people are at a crucial point in their education / career on the brink of independence and heavily reliant on their peers. There has been a huge tidal wave of TYA development in the UK over recent years in response to the recognition of the unique needs of this group of patients.

A bit of History.....

The first Teenage Cancer Unit in Leeds opened in 1998. At that time it was a 6 bedded unit at the end of the Paediatric Oncology/Haematology Ward taking patients from 13 to around 21 years if there was bed capacity, with the under 18's taking priority. In the same year Sue Morgan was appointed as the first Macmillan TYA CNS and in 1999 a Malcolm Sargent Social Worker was employed forming the basis of the TYA service we have now. In 2001 our first Activity Co-ordinator was appointed and as referrals increased, it quickly became clear that the 18- 24 year olds had very similar needs so a second TYA CNS was appointed to support the older TYA's inside and outside the Trust, making the service truly peripatetic. In 2004 the first ever Learning Mentor for TYA's was appointed, funded by the Emma Maltby memorial fund and supported by Education Leeds and in 2005 a Macmillan Clinical Psychologist was employed specifically for our TYA patients. In 2006 another CNS was appointed to develop out patient services for TYA's and in 2007 a second Social Worker came in to post.

After much anticipation in January 2008, the 2nd TCT unit opened in the new Oncology Wing at St James's hospital. This 9 bedded unit was developed to care for our 18-24 year olds. In the same year TCT funded a Nurse Consultant post for the region and a Youth Support Co-ordinator for the new ward. By 2009 a Macmillan TYA CNS was appointed as Team Leader and in 2010 a new TCT Unit for 13-18 year olds was opened at the Leeds General Infirmary to replace the one at St James's when Children's services were moved across the city. In 2010 a TYA MDT Co-ordinator completed the current team.



The Leeds Teenage Cancer Trust Units, Ward 78 and Ward 94



There are 2 inpatient facilities in Leeds.

A nine bedded Young Adult Ward for 18 – 24 year olds - Ward 94 and an eight bedded Teenage Ward For 13 – 18 year olds - Ward 78.



Both of these facilities have

been funded and designed by the Teenage Cancer Trust, a charity devoted to improving the lives of young people with cancer.

The Units are dedicated to teenagers and young people and have been designed with the help of patients and their families. The aim is to provide patient care in a friendly uplifting environment, with other patients of the same age.



THE YOUTH SUPPORT CO-ORDINATOR ROLE.....

The Youth Support Co-ordinators (YSC's) organise a number of events and activities for both patients and their families.

When a teenager or young adult is diagnosed with cancer, it is often a time when they are at their most socially active, be it college, university or going out after work or at weekends with their mates.

Young people often feel unable to keep up with their friends due to the physical and emotional effects of their diagnosis and treatment. This can have a huge impact on their social life.

The plan social events on and off the ward giving young people an opportunity to spend time with others who are going through a similar experience.

The activities are varied to suit different needs and ages. Most importantly we have these activities so they can mix, socialise with their peers, relax, have fun and be distracted while they are having treatment. If anyone would like to get involved as a patient or volunteer, please contact our YSC's Cat or Carrie cat.carroll@leedsth.nhs.uk 0777557296 carriann.pointer@leedsth.nhs.uk 07879385308.

OUT AND ABOUT.....



- Alton Towers
- Biffy Clyro at Teenage Cancer Trust Royal Albert Hall
- Teenage Cancer Trust Focus weekend at Low Mill in Yorkshire
- Indoor Golf in Leeds
- Sailing with Ellen McArthur Trust



- Knowsley Safari Park trip
- Flawless at West Yorkshire Playhouse

- Barge Boat trip, Steam Train trip



Family Day

On the ward in 2011.....

Sound workshops

Card making



- Take-a-way nights
- Media workshops
- Craft workshops
- Scrapbook project

- Art workshops
- Textile workshops
- Movie nights
- Sweet making



- Mosaic workshop
- Garden project
- Guy Fawkes competition
- Bonfire tea

- Baking/Cooking
- Close up magic
- Jewellery making
- Pottery



- Look Good Feel Better
- Guitar lessons
- Breakfast café
- Textiles workshops
- Complementary therapies every week
- Themed Parties

- Halloween Party
- Body Shop Party
- Smoothie Making
- Music/DJ workshop
- PJ parties



Joe McElderry Visit!



Find Your Sense of Tumour (FYSOT) is a national conference for Teenagers and Young Adults who have or have been recently treated for cancer. It is held annually over a weekend at Center Parcs in Sherwood Forest, Nottingham. The weekend is a mix of formal presentations and social activities with com-

plementary therapy sessions, a range of activity workshops plus plenty of free time to enjoy the facilities at Center Parcs.

The weekend provides an amazing opportunity for young people living with a cancer diagnosis to address the issues that are important to them.

The next FYSOT is February 24th to February 27th 2012

For more information please contact Cat or Carrie at cat.carroll@leedsth.nhs.uk on 07775572960 or carriann.pointer@leedsth.nhs.uk on 07879385308.



Some Facts and Figures.....

Cancer is the leading natural cause of death in young adults up to the age of 24.

6 TYA's per day are diagnosed with cancer. 2200 TYA's a year die from cancer and in the last 30 years the numbers of teenagers and young adults with cancer has increased by 50% so that there are now more teenagers with cancer than there are children with cancer.

TYA Cancers

15-19 years

Lymphomas 27.3%

Sarcomas 16%

Leukaemia 15.1%

Carcinomas 11.3%

Brain Tumours 10.8%

Germ Cell Tumours 9.6%

Melanoma 5.9%

Others 4%

20-24 years

Lymphoma 24%

Carcinomas 21.1%

Germ Cell Tumours 16.9%

Melanoma 10.1%

Sarcomas 8.1%

Leukaemia 7.7%

Brain Tumours 7.7%

Others 4.4%

Several of these cancers have their peak incidence in the TYA age group, including Hodgkin's disease, Osteosarcoma, Ewing's Sarcoma, Germ Cell Tumours.

Current open treatment trials at Leeds Principal Treatment Centre for TYA patients

EURONET for Hodgkin's Disease -up to 18 years for (primary therapy), no upper limit for relapse therapy and **RATHL** trial for 18 years and over

SGN-35-005 trial for patients post transplant with Hodgkins Disease

R CODOX M IVAC for DLBCL/Burkitt's Lymphoma - for 18 years and over

High Risk Neuroblastoma trial- up to 21 years

LGG2 for Low Grade Glioma - up to 25 yrs in observation study but up to 16 years for patients who are to be randomised.

AML 17 - closed for under 16 years, open for over 16 years

EUROEWING'S 99 for Ewing's Sarcoma, -up to 40 years

EsPHALL trial for Philadelphia positive Acute Lymphoblastic Leukaemia- up to 17 years

UKALL 14 over 21 years

R3 trial for Relapsed ALL- up to 18 years

RMS 2005 for non-metastatic Rhabdomyosarcoma - up to 21 years

NRSTS for Non Rhabdomyosarcoma soft tissue sarcomas - up to 21 years.

The Leeds TYA MDT

The TYA MDT meets every Thursday at 2.45pm. It is a cross city meeting using video conferencing facilities between the Paediatric Radiology Suite in Clarendon Wing at the LGI and the Cookridge Conference Centre on Level 07 Bexley Wing at St James's Hospital.

The function of the TYA MDT is to review the presentation, pathways, diagnostic material (radiology and pathology) and care of all referred patients aged 13-24 inclusive within the Yorkshire Cancer Network and the Humber and Yorkshire Coast Cancer Networks, as defined in the NICE Improving Outcomes Guidance for Children and Young People (2005)



Our TYA MDT has been running since 2008 bringing together staff with the necessary knowledge, skills and experience to ensure that we are providing the best possible care for our young people. At the same time it provides a valuable shared learning opportunity between paediatric and adults, also enabling a smoother transition from paediatrics to adult services.

The TYA referral pathway, MDT alerts and MDT referral forms can be found on the Yorkshire Cancer Network and on the Humber and Yorkshire Coast Cancer Network websites.

It is important that we are informed about any Teenagers and Young Adults diagnosed with cancer, not only so that we can make contact and support them but it is also a national requirement for all 15-24 year old newly diagnosed patients to be registered with TYAC. See more info re; TYAC on back page. The aim of the TYAC notification form is to help measure the level of access to TYA specialist care and to inform decision making around TYA cancer services. The TYAC referrals are completed once a patient has been discussed in the TYA MDT.

Kirsty Faircliffe, TYA MDT Co-ordinator is responsible for registering all patients in the Yorkshire and Humber region regardless of where they are being treated.

Kirsty can be contacted on 0113 3922327 or via email kirsty.faircliffe@leedsth.nhs.uk

The TYA Measures and Designation.....

Couldn't really complete this news letter without some mention of the TYA Measures!

As you will be aware the TYA measures were published in July 2011. Here at the PTC we have just been through the first round of internal validation and the designation process is ongoing.

The NICE Guidance on Improving Outcomes in Children and Young People with Cancer (the CYPIOG), requires a set of arrangements to be made for the age group of patients, from 16 to 24 years for the diagnosis and management of cancer. The measures recognise 'one of the key added values intended to flow from these arrangements is the provision of an age-appropriate environment and support network for these patients, some of whose needs are rather specific to people at this time of life as they make the transition from childhood to adulthood'.

One issue for implementing the service changes for young adults, as recommended by the CYPIOG, is to achieve the advantages of an age-appropriate environment and support network but without losing the advantages which have come in adult cancer treatment.

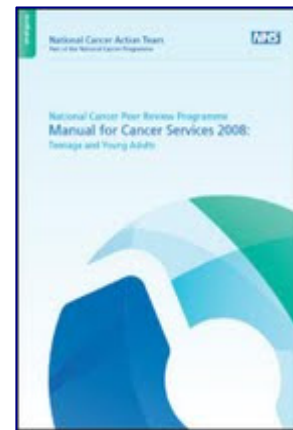
The measures go on to describe the 'Shape of the Service' which should include

- a single TYA PTC on the same site as the Children's PTC
- an overall TYA co-ordinating group for the cancer network
- minimum requirements for staff and dedicated in patient and outpatient facilities
- a dedicated TYA MDT

Designation of hospitals outside of the PTC, by the coordinating group, for care of 19 -24 year olds should they choose not to have their treatment in the PTC. These hospitals would then be subject to their own specific set of measures.

The first official TYA Cancer Network Co-ordinating Group met on October 13th this year where some of the issues around designation were discussed at length.

The PTC is keen that all our local hospitals agree to designation so that we can continue to build strong working relationships and in the spirit of the measures be able to offer patients the choice of having their treatment as locally as possible, whenever possible, with unhindered access to age appropriate support when needed.



If you require any further information or support regarding designation and shared care please do not hesitate to contact ;

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Check out these websites.....



The Teenage Cancer Trust understands that young people with cancer require specialist care, that young people have a much better chance in their fight against cancer if they are treated by teenage cancer experts, in an environment tailored to their needs. They fund and build specialist units for young people in NHS hospitals. These units bring teenagers with cancer together so they can support each other. They also fund 12 Nurse Consultant posts and several Youth Support Coordinator posts around the country. Teenage Cancer Trust units aren't like ordinary cancer wards. Everything about them has been designed to give teenagers the very best chance of a positive outcome. The Teenage Cancer Trust aims to ensure that every young person with cancer and their family receive the best possible care and professional support throughout their cancer journey. www.teenagecancertrust.org

Upcoming Educational Events!

TYAC Spring Education Day
20th April—Nottingham

Teenage Cancer Trust 7th International Conference
25th and 26th June 2012 at the Royal Society of Medicine in London.



'Teenagers and Young Adults with Cancer' (TYAC) was established to help all professionals involved in the care of young people with cancer to work together to improve knowledge and services. TYAC was formed in 2004 in response to concerns amongst health carers that the needs of teenagers and young adults with cancer were not being met and could be better understood. TYAC raises awareness of the need to provide appropriate care for young people by improving communication between stake holders, advocating for teenagers and young adults and professionals and by promoting research, education and information. TYAC offers National conferences, seminars and workshops, meetings between professionals, a Website, a weekly e-bulletin and newsletter for members. www.tyac.org.uk

And these.....



CLIC Sargent is a charitable organisation which offers all round care and support to children and young people with cancer and their families. They provide specialist nurses, play specialists, social workers and Homes from Home. They offer specialist social care and support in the community – services for young people, holidays and grants and following treatment helping survivors and supporting those bereaved. www.clicsargent.org.uk



Cancer care choices for young people. A website aimed at 19-24 year olds diagnosed with cancer, to help guide them through the decisions they might make about where to be treated and cared for. Includes videos of young people sharing their experiences of cancer treatment in various settings. www.nhs.uk/youngcancercare



Established in 1976, Candlelighters is a charity formed and run by parents of children who have or have had cancer, ex-patients and the medical staff who treat them. Based in Yorkshire, Candlelighters provides essential services and support to children with cancer and their families. www.candlelighters.org.uk



Jimmyteens.tv is a project aimed at educating people about the effects of cancer; not just the medical effect, but also the emotional effects upon the patient and their friends, family, doctors, nurses, or anyone surrounding them. The project was started in 2005 by Mark Wilkinson and the staff of the Leeds, Teenage Cancer Trust Unit at St James's Hospital, hence the name *jimmyteens*, after seeing the benefits of creating video diaries whilst creating the BBC documentary To Courtney with Love. Leeds based charity Candlelighters stepped in to provide funding and jimmyteens.tv is now also supported by the Teenage Cancer Trust as well as many other charities. The project has grown from strength to strength, employing 6 people full time, who have had, or have been affected by cancer. In the past year jimmyteens.tv has also started broadcasting live shows some serious – such as the Debate which discusses pertinent issues facing cancer patients today, and more light hearted programming. In 2010 the work of jimmyteens.tv was recognised by winning the "Excellence in Oncology – Best Charitable Initiative" award. www.jimmyteens.tv