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Introduction to Teenage Cancer Trust

Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and outcomes for the seven young people aged between 13 and 24 diagnosed with cancer every day. We fund and build specialist units in NHS hospitals and provide dedicated staff, bringing young people together so they can be treated by teenage cancer experts in the best place for them. Through education of young people about the signs of cancer and working with health professionals to improve their knowledge, we work to significantly improve their diagnosis experience.

There are around 2,500 young people diagnosed with cancer each year across the UK. In Scotland approximately 203 new patients in this age group will be diagnosed annually, while approximately the same number again will continue to receive care for cancer or relapseⁱ. Patients aged 13-16 will be managed within the four children's hospitals in Scotland; the two Principal Treatment Centres for cancer in Glasgow and Edinburgh which have Teenage Cancer Trust units with Teenage and Young Adult Multi-Disciplinary Teams (TYAMDTs), Aberdeen and shared care in Dundee. Teenage Cancer Trust units at the Edinburgh Western General and Glasgow Beatson West of Scotland Cancer Centres are amongst the hospitals that provide care for 16-24 year olds, but this age group's care is more scattered.

Transition for teenagers and young adults with cancer

Young people with cancer may transition between paediatric and adolescent oncology services, between adolescent and adult services, or in some cases directly between paediatric and adult care. These periods of transition may occur during the same treatment phase, or a young person may relapse and return to access treatment and care within a different part of the health service. When managed appropriately, the young person will experience a flexible transition, retaining choice and control. When this is not achieved, however, the patient and their family can experience anxiety, may feel they lack required information, may lose trust in the professionals leading their care, and can suffer delays in accessing treatment and services.

The current body of work on transition for young people with cancer includes the Blueprint of Care for Teenagers and Young Adults with Cancerⁱⁱ, the Teenagers and Young Adults with Cancer Professional Group (TYAC) best practice statement on transitionⁱⁱⁱ, NICE Improving Outcomes Guidance for Children and Young People with Cancer^{iv}, and the Managed Service Network's Cancer Plan for Children and Young People^v. Much of the information in this written statement encapsulates elements of these existing guidelines.

Key actions for successful transitions

Transition should never be a surprise to a young person. It should be a staged process, carefully planned to ensure all those involved understand what is happening, from a patient and clinical perspective. It shouldn't happen overnight once a person turns a certain age. A successful transition involves the young person being engaged in dialogue about transition from an early stage, including the provision of literature in accessible formats; the identification of an appropriate key worker to accompany the young person to visit the new environment and team, and to attend the patient's first session in the new service; a holistic transition (incorporating nursing, social work, youth work, physiotherapy, dietician etc); and medical teams from both the existing and new services discussing treatment plans together. All this activity should be underpinned by a robust transition operating procedure.

Why successful transitions do not occur

An inadequately managed transition can detrimentally impact on the patient and their experience of care; this may manifest itself psychologically, on the new clinical and holistic relationships they need to form and how they adhere to treatment. A transition may be unsuccessful if any one of the key actions is not in place. For example, whilst a holistic MDT should be in place for paediatric and adolescent services, additional psychosocial, family and advocacy support may be non-existent within an adult setting. When explaining transition to young people difficulties can also occur; evidence demonstrates that young people with cancer consistently report worse experiences with regard to communication, particularly when explanations of treatments, condition and tests are not delivered in a way which recognises the lack of hospital experience many young people will have at the time they start treatment.^{vi}

The effectiveness of existing professional guidelines and patient pathways

An important step to improve transition for young people with cancer would be the more stringent implementation of the Managed Service Network's Cancer Plan for Children and Young People. The Plan recommends that all young people with cancer, up to the age of 25, be treated within age appropriate services. The different pathways that young people between the ages of 16 and 24 can currently take are a key challenge to this, and therefore to successful transition. Not all young people with cancer will be treated in an age appropriate environment, and this can affect their transition experience. We need to ensure that all young people have equity of care, as well as in transition; and this requires a consistent pan-Scotland approach.

What more could the Scottish Government and NHS Boards do to promote and bring about better transition services?

The number of young people with cancer in Scotland is small, yet the scale of variation in their experience disproportionately large. There are pockets of good practice in transition, both within and outwith cancer, currently happening in Scotland and elsewhere in the UK. We would advocate that this good practice is actively supported and rolled out across the rest of Scotland.

In order to achieve this it will be vital for NHS Boards and clinicians to ensure widespread adoption of existing guidance and best practice and to support innovative solutions to on-going difficulties in transition. Teenage Cancer Trust has been piloting a new model of care which delivers a holistic service designed with patients at the centre. The central tenet of this model is to ensure that every young person with cancer is discussed by a TYAMDT regardless of where they receive their treatment, and this process will enable all patients to access the expert clinical care required for an improved patient experience throughout their pathway; including during transition.

Within the current system in Scotland, each NHS Board needs to bring paediatric and adult services together to better understand how care is delivered on each 'side', and through this understanding, jointly deliver a transition process that puts patients truly at the centre. This activity needs to be underpinned by the collection of patient feedback on outcomes linked to transition via tools such as Quality Performance Indicators, and this feedback then acted on to drive improvements.

We welcome the Health and Sport Committee, the Scottish Government, and NHS Boards undertaking this evidence gathering, and very much support the aim to promote and improve transition services in Scotland.

ⁱ Information Services Division, NHS National Services Scotland (2013), *Cancer in Scotland (2011)*

ⁱⁱ Smith S, Case L, Waterhouse K, et al. (2012) *A Blueprint of Care for Teenagers and Young Adults with Cancer*. Teenage Cancer Trust and TYAC

ⁱⁱⁱ Langford C and Wright D. (To be published 2014) *TYAC Best Practice Statement: Transition*

^{iv} National Institute for Health and Clinical Excellence (2005), *Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer*

^v Managed Service Network for Children and Young People with Cancer in Scotland (2012), *Cancer Plan for Children and Young People in Scotland 2012-15*

^{vi} Department of Health (England) (2010, 2012 and 2013), *National Cancer Patient Experience Survey*