Children, teenagers and young adults (0-24yrs): overview

Children, teenagers and young adults are a relatively small proportion of all cancer patients, defined as rare or less common cancers. It is easy for them to be lost in a system not designed for them and without specific focus on their needs.

There are around 180\(^1\) new diagnoses each year of cancer in 0-24 year olds, with many more on active treatment at any one time. Although survival rates are over 80%, cancer remains the single largest cause of death from disease in children in the UK. It is recognised, most notably in best practice NICE guidance\(^2\), that there is a particular psycho-social impact of cancer on children and young people.

Cancer Delivery Plan\(^3\)

The Wales Cancer Alliance noted the very limited focus on children and young people with cancer and their families in the Cancer Delivery Plan. The Health & Social Care Committee’s inquiry report into the implementation of the Cancer Delivery Plan (October 2014) also noted the lack of focus on children and young people and that this has meant that progress cannot be accounted for.

For example, we welcome the strong focus within the Cancer Delivery Plan on data collection and evidence and on gathering patient-reported experience data. However, progress has not been made in this area for children, teenagers and young adults, and barriers to effective collection and sharing of data and evidence remain for this age group. In addition, the Wales Cancer Patient Experience Survey did not include children aged 0 to 16 or their parents.

The Alliance supported the Welsh Government’s National Standards for Children with Cancer and which were published in March 2011 and the National Cancer Standards for Teenagers and Young Adults which were published around 2013. However, despite these standards being published there has been no formal launch, dissemination or measurement of the standards which leaves children and young people’s cancer services at risk of failing to meet the standards with no means of accountability.

Background

Unlike adult cancers, the focus for the planning and delivery of cancer treatment for children is based in a few very specialised principal treatment centres (PTCs), of which there are currently 18 in the UK and one in Wales (Children’s Hospital of Wales, Cardiff). Teenagers and Young Adults in South Wales will usually have their treatment managed by the Teenage and Young Adult Multi-Disciplinary Team at the University Hospital of Wales, Cardiff.

Whilst this means that specialist expertise has been developed in these centres, it also means that many children are treated in hospitals hundreds of miles from home. Many children and young people with cancer in Wales may receive at least some of their treatment in one of the PTCs in England, such as Alder Hey for those from North Wales, or those who require bone marrow transplant from South Wales will need to go to Bristol. Teenagers and young adults from North Wales may receive their treatment in hospitals in Liverpool, Manchester or Birmingham.

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\(^2\) NICE (2005) *Improving Outcomes in Children and Young People with Cancer*, London: NICE.

As well as specialist support that can be provided in PTCs, shared care arrangements also exist whereby patients can have some elements of their care delivered in designated shared care units, such as Ysbyty Gwynedd in Bangor, Wrexham Maelor Hospital and Glan Clwyd Hospital in Rhyl.

**Calls for action**
The Wales Cancer Alliance calls for:

1) **Clear policy commitments and accountability framework**
   Any new cancer strategy must include defined commitments to understanding and meeting the needs of young cancer patients to ensure there is a clear, coordinated approach to providing high quality services are accessible to all. These commitments should seek to address the key issues for children, teenagers and young adults with cancer identified below. The Welsh Government has also now published an Implementation Plan for Rare Diseases which contains important policy commitments to patients with rare diseases and should be cross referenced with the Cancer Delivery Plan.

2) **National standards to be implemented, measured and reported on**
   A peer review process should be made operational as a matter of urgency to assess children and young people’s cancer services against the national standards and reported against both publicly and to the Chief Executives of LHBs.

In addition to these there are also several specific challenges around supporting younger cancer patients:

- **Early diagnosis**: A greater focus on improving diagnosis of cancer in children, teenagers and young adults is required due to particular challenges in identifying cancer in this age group. Research is needed to establish optimum routes to diagnosis for children, as the links between particular routes to diagnosis and survival and long term health outcomes have not been sufficiently explored for this age group. In addition to improving the availability of diagnostic testing in primary care settings, it is essential that GPs and other primary care professionals have access to the training and support that they require to feel confident in identifying the signs and symptoms of cancer in children, teenagers and young adults. It is also essential that young people and families are aware of cancer symptoms to empower them to seek help when needed.

- **Access to clinical trials for 16-24 year olds**: Improved access to clinical trials is a direct way to improve patient experience, outcomes and ultimately survival for teenagers and young adults with cancer. However, young people with cancer have very low levels of participation in trials. Figures published in 2014 show only around 30% of teenagers aged 15-19 and 14% of young people aged 20-24 in England, Scotland and Wales enter trials for cancer types which are common in young people. 4 5

- **Survivorship**: It is important to recognise that the survivorship experience for young cancer patients is likely to be different than that of older adults, largely because most young cancer survivors will require additional and long-term support for potentially 50+ years. A significant proportion will also go on to develop other long-term conditions and are at high risk of cancer recurrence in later life. The wider use of patient held records and summary care plans can help empower patients in managing their care needs post-treatment and beyond.

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• **Palliative care**: Children, teenagers and young adults with palliative and end of life care needs should have access to palliative nursing care 24/7 and access to paediatric advice and support 24/7. Outreach nurse specialists and children’s community nurses (CCNs) play a vital role in the coordination of palliative and end of life care, and in supporting children to die at home if they choose to. However, outreach nurses are not available in all areas of the country and are very often reliant on charities for funding, and there are limited numbers of CCNs in place across Wales. Provision is particularly limited for young people aged 16 to 18, as only children aged up to 16 are eligible for children’s services, and only those aged 18 and above are able to access adult palliative care provision. Finally, there is a lack of availability of age appropriate hospice care for 16 to 24 year olds with cancer.\(^6\)

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\(^6\) Grinyer, A. & Barbarachild, Z. (2011) *Teenage and Young Adult Palliative and End of Life Care Service Evaluation*, Teenage Cancer Trust / Lancaster University.