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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal
Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: CLIC Sargent

Response from: CLIC Sargent

CLIC Sargent submission to Consultation on Priorities for the Health, Social Care and Sport Committee – September 2016

Introduction

1. CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. We provide emotional, practical, financial and clinical support to help them cope with cancer and get the most out of life. We are there from diagnosis onwards and aim to help the whole family deal with the impact of cancer and its treatment, life after treatment and, in some cases, bereavement. Last year we supported over 7,000 children, young people and their families.

2. CLIC Sargent plays a key role in providing care and support to the children and young people diagnosed with cancer in Wales each year.¹ Last year we supported more than 280 children and young people with cancer and their families from Wales. We gave over 270 grants to a value of over £55,000 to help families deal with the financial impact of cancer. CLIC Sargent invests £300,000 in direct services and financial support to children and young people with cancer in Wales each year and our services in Wales include:
 - We contribute to the funding of three Clinical Nurse Specialists and a Paediatric Social Work post supporting patients in shared care arrangements throughout North Wales
 - We have a fund a Young Persons Social Worker for the North Wales region.
 - We have a Young Person's Outreach Team in South Wales consisting of two Young Person's Social Workers and a Care Support Worker supporting 16-24 year olds affected by cancer.
 - We fund a Paediatric Neuro-Oncology Nurse Specialist Key Worker in South Wales.
 - We cover the paediatric principal treatment centre in Cardiff as well as supporting patients in shared care arrangements in Bangor, Wrexham and Rhyl.

3. CLIC Sargent welcomes the opportunity to input into the Consultation on priorities for the Health, Social Care and Sport Committee. There are a number of priorities concerning children and young people with cancer in Wales that we would appreciate the Committee looking into. They include:
 - The financial impact of cancer for young people and their families.
 - Teenagers and young adults (TYA) with cancer being able to access the care they require, in appropriate settings.
 - Children, young people and parents' experiences of cancer diagnosis.
 - Lack of data on patient experience for children and young people.

¹ There are around 170 new diagnoses in Wales each year in the 0-24 age-group.

The financial impact of cancer for young people and their families

On 1 September, to coincide with Childhood Cancer Awareness Month, CLIC Sargent published new research into the financial impact of cancer for young people and their families.

Our research, *Cancer costs: the financial impact of treatment on young cancer patients and their families*, explores the rising costs for young people and their families when they are going through cancer treatment, as well as the decreasing income. Please find attached an embargoed copy of the report.

The **key findings** of the report include:

- Parents spent an average of £600 additional expenses a month during their child's active treatment.
- Three in five (61%) parents had accumulated some form of debt as a result of their child's cancer diagnosis, mostly owed to family and friends or to credit card companies. One in six (17%) had borrowed over £5,000.
- As a result of their child's cancer diagnosis, two in five (42%) parents stopped working, half (49%) experienced a loss of earnings, and almost a third (29%) felt they were able to do less at work.
- The top three financial worries for parents were energy bills, car-related costs and parking.
- Three-quarters (75%) of parents and over half (54%) of young people surveyed felt that managing their finances during treatment caused them additional stress and anxiety.
- Almost a third of parents (29%) were not offered parking exemptions at their main treatment hospital, despite government guidance to hospitals.
- Nearly half of young people who were in higher or further education deferred or suspended their studies during treatment. Almost a third (29%) ended their studies completely, while one in six (16%) continued in a reduced or part time way.

Our **key recommendations for change** for governments across the UK are:

1. The government should conduct an urgent review of all travel assistance available to parents and young people, and make recommendations for reform by the end of 2017.
2. Financial services and energy companies should review their vulnerable customers' policies to ensure they include parents of children with cancer and young cancer patients.
3. The government should review the financial support available for young cancer patients and their parents who are struggling to meet the costs of their energy bills.

We don't think it is right or fair that young cancer patients and their families are impacted to such an extent financially because of their cancer diagnosis. We would encourage the Committee to look into this issue more deeply.

Teenagers and young adults (TYA) with cancer being able to access the care they require in appropriate settings

4. Despite the fact that national standards for the management of TYA have now

been put in place, minimal progress has been made to increase access to the specialist support available to the 16 – 24 age group. TYA multi-disciplinary teams (MDTs) exist in South Wales (at University Hospital of Wales) and in the Clatterbridge hospital on the Wirral (to which North Wales young people would be referred). The recommendations that all TYA diagnosed with cancer should be referred to the TYA MDT's is not being complied with in many cases. For example North Wales Cancer Network has identified 10 young people who have been diagnosed with cancer in the past year who have not been referred to the TYA MDT. Analysis of this information is on-going to identify why this is the case. Overall in Wales we believe that at least a third of young people with cancer are not referred to their specialist TYA MDT for support, creating an inequity in service and depriving young people of choices in their cancer care delivery and support.

5. CLIC Sargent and Teenage Cancer Trust have been working together to raise awareness of this issue and we support their submission to the Committee for this consultation as well. We have written together to the Cabinet Secretary for Health, Wellbeing and Sport on this issue (the text of this letter is pasted below).

Dear Mr Gething

Congratulations on your re-election and appointment as Cabinet Secretary, it's great to have someone with your background and knowledge about cancer services in Wales in this important role and we very much look forward to working with you.

Teenage Cancer Trust and CLIC Sargent are the two largest charities representing the needs of children and young people with cancer in Wales and across the UK. We are members of the Wales Cancer Alliance and work in partnership to influence policy and deliver in practice to ensure all children and young people with cancer have access to services that meet their needs and support them to live their lives to their full potential.

The next few years are critical to embedding changes in Welsh Cancer Services that could make real improvements for young people with cancer and their families; and there is much to be done. There are around 180 new diagnoses of cancer each year in 0-24 year olds, with many more on active treatment at any one time. Although survival rates are over 80% on average cancer remains the single largest cause of death from disease in children in the UK and for some cancers survival is as low as 50%. Very few young people are being picked up by traditional methods of assessing services, like peer review and the Cancer Patient Experience Survey, and many children and young people are having to travel hundreds of miles from home to access support.

We've been very disappointed that children, teenagers and young adults have had so little focus in the Cancer Delivery Plan and lack of priority gives to these areas of improvement. This must change in order for young people with cancer to have their needs met.

A commitment from the Welsh Government to referring every patient to a paediatric or teenage and young adult MDT should be made a priority for health boards which they are measured against. This one commitment will help NHS services know where

each patient is, be able to offer them support and access to research as well as follow up with them after treatment. It will also enable us, as charities, to provide much needed specialist care and support to them through our work with the MDTs are the designated Principal Treatment Centres.

We call on you to champion the needs of this vulnerable group of patients who too often fall between services and priorities leaving them disadvantaged and missing out on support that is available to them.

If you would like to meet to discuss this then we are very happy to do this at your convenience. We're aware the Cancer Delivery Plan is due to be refreshed and so are keen that this one commitment is part of any new plan or strategy.

6. In order to ensure improvements in outcomes for TYAs it is essential that action is taken to ensure that the recommendation for referral to specialist age appropriate care and support to be enforced. ***This is the single most important action that could be taken on behalf of young people with cancer in Wales.*** Without all Health Boards being held to account for their inaction to achieve 100% referral of 16-24 year olds to the appropriate TYA MDT, outcomes cannot be improved within this age range. Young people will also not be able to access specialist support services or relevant clinical trials until this is achieved.

Children, young people and parent's experiences of cancer diagnosis

7. In the current plan there are some important actions around earlier detection, such as a commitment to 'raising GP awareness of symptoms to promote prompt referrals in line with national guidance, local pathways and waiting times standards', 'Auditing the pathway for each person diagnosed with advanced cancer and act on findings to improve services for early diagnosis' and 'Developing acute oncology services to support the needs of people admitted as emergencies'.

8. CLIC Sargent research, *Best Chance from the start*, we highlighted the fact that children aged 0 to 14 in England² are more than twice as likely to be diagnosed through emergency presentation as young people aged 15 to 24 (53%), for whom 25% are diagnosed through emergency presentation, and older adults, who have emergency presentation rates of 20%³. The impact of the disproportionate rate of emergency presentations on prognosis and outcomes for children has not been established. However, we do know that stress and anxiety caused by delay can have a profound effect. In addition, our research also found that Young people and their families have reported not feeling listened to or taken seriously when they first presented their symptoms to their GP, and that GP's themselves ranked lack of training available as one of their top three barriers to identifying cancer in children and young people.

9. We believe that clear commitments are needed to tackle disproportionate rates of emergency presentation, including undertaking a Significant Event Analysis for patients diagnosed following emergency presentation, improving initial and ongoing training in children and young people's health for primary care

² This routes to Diagnosis study only looked at England data although we would expect the picture would be very similar in Wales and the other UK nations

³ <http://www.clicsargent.org.uk/content/better-care-young-cancer-patients-diagnosis>, Page 7

professionals and reporting on the level of access that GP practices have to paediatric and young people’s health expertise.

Lack of data on patient experience for children and young people

10. It is regrettable that the recently published Wales Cancer Patient Experience Survey did not capture the experiences of patients who are under 16 years old. Patient experience is rightly valued within the health system in Wales, however, children do not have this opportunity to share their experiences and the lack of information about the current state of patient experiences of children under the age of 16 is a significant barrier to improvement. Without national patient experience data it is difficult to develop meaningful indicators to drive improvements in children’s cancer patient experience. NHS England has said they will develop a methodology to collect data on patient experience for under 16s in 2017⁴. We believe that Wales should make a similar commitment. CLIC Sargent has also already done work on what a methodology for collecting data from patients who are under 16 could look like and would be happy to share this with the Welsh Government.

11. Although the Wales Cancer Patient Experience Survey did include 16 – 24 year olds, the number of young people responding to the survey is low. One reason for this might be that the survey is not age appropriate and that young people find it difficult to engage in an adult survey. The Cancer Patient Experience Survey which is operated by the NHS in England has consistently shown that TYA with cancer report poorer patient experiences than older adults. Consequently, it is critical to gauge whether this is also the case in Wales, and to take action to address any inequality of patient experience for TYA.

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⁴ Achieving World-Class Cancer Outcomes: Taking the strategy forward, Five Year Forward View, NHS England, May 2016