

Teenage Cancer Trust Consultation Response:

Relationships Education, Relationships and Sex Education (RSE) and Health Education - November 2018

Consultation question 14: Do you agree that the content of RSE as set out in paragraphs 65-77 of the guidance will provide secondary school pupils with sufficient knowledge to help them have positive relationships?

[Disagree]

Teenage Cancer Trust does not agree that the content set out under these paragraphs will provide secondary school pupils with sufficient knowledge to help them have positive relationships, because it does not take account of the impact that a long-term physical health condition such as cancer can have on forming and maintaining such relationships.

Teenage Cancer Trust would like to see cancer addressed specifically as part of guidance for health (and relationship) education in secondary schools.

Young people connected with Teenage Cancer Trust consistently tell us that they find transition after treatment one of the hardest parts of the process - often because they felt that those around them didn't understand them.

At the most recent meeting of our Youth Advisory Group young people frequently highlighted that having education for them, their peers and their educators on forming positive relationships after cancer would be one of the most beneficial things to help them get back on track.

One young person told us they would've liked to have support in school on 'understanding the impact cancer would have on personal relationships – families and friends', another raised the need for 'better education of [their] needs within [their] school', another that '[the burden] shouldn't have to sit with [us] to communicate the challenges with transition', and another that 'there should be better messaging about transitioning back into work and school'.

Young people recovering from cancer want to be equipped to form positive relationships going forward, and help others better understand what they have been through, and where they are going. We would like to see forming positive relationships with young people who have experienced long term physical health conditions reflected in the guidance.

Young people with cancer have told us that Teenage Cancer Trust's 'Mates Matter' programme is a highly effective example of how to help young people better understand cancer, the difficulties young people with cancer face in transitioning back to normal amongst their peers and schools, and how to form positive relationships.

Following a Mates Matter presentation, young people have told us that they 'think [their] friends are now less intimidated about talking about cancer'ⁱ and that 'more people offer to help [them] after the presentation and it has benefited [them] by people having a greater understanding'ⁱⁱ.

It should also be considered that it is not just young people with cancer whose mental wellbeing can suffer directly, but it can also impact on relationships at home. Young people who have a parent or sibling with

cancer are three to six times more likely to have mental health problems than their peersⁱⁱⁱ. Young people often speak to Teenage Cancer Trust about the guilt they feel for what they perceive as ‘burdening’ their family with their condition. After attending one of our presentations 63% said they felt more confident talking about cancer with friends or family.^{iv}

Given that 12% of young people manage a long-term physical health condition such as cancer, it is essential that guidance considers the wider impact such a condition can have on young people’s ability to form and maintain positive relationships. Teenage Cancer Trust’s education and awareness programme demonstrates how this can be done, and the positive impact it can have on young people.

Consultation question 18: Do you agree that the content of physical health and wellbeing education as set out in the guidance is age-appropriate for secondary school pupils?

We welcome the decision to make Health Education compulsory in all state-funded secondary schools, and our experience of delivering our cancer programme in secondary schools gives us confidence that the areas suggested in the guidance are age-appropriate for secondary school pupils.

Teenage Cancer Trust have been delivering a pioneering Education and Awareness programme in secondary schools across the UK for over 15 years. We educate young people about the signs and symptoms of cancer, healthy lifestyle choices which can prevent certain causes of cancer and give them confidence to go to the doctors.

Consultation question 19: Do you agree that the content of physical health and wellbeing education as set out in the guidance will provide secondary school pupils with sufficient knowledge to help them lead a healthy lifestyle?

Teenage Cancer Trust does not believe that the content set out provides pupils with sufficient knowledge to help them lead a healthy lifestyle because several crucial, potentially life-saving elements of cancer awareness are not included.

Teenage Cancer Trust would like to see cancer addressed specifically as part of guidance for health education in secondary schools. Cancer is the biggest killer of young people by disease as well as going on to affect 1 in 2 adults. Guidance should be wider than just promoting living healthily, and should include: understanding signs and symptoms of cancer (particularly those that are likely to affect young people), developing confidence to go to the doctors about health concerns, understanding the relationship between physical health and mental health, and support for forming positive relationships during and after cancer.

Where cancer is referenced in relation to making healthy lifestyle choices in the draft guidance, Teenage Cancer Trust is supportive of the content. But whilst healthy lifestyle choices can help to prevent causes of certain types of cancer in adulthood, this addresses only a part of the overall picture.

Young people experience rarer, less common and harder to diagnose cancers such as leukemias, lymphomas and myelomas. Most of these cancers are not preventable through lifestyle choices – so it is absolutely crucial that health education makes young people aware of the cancers most likely to affect

them, as well as understanding how to spot signs and symptoms, and act to ensure they are diagnosed as early as possible, in order to help increase survival chances.

Early diagnosis is important because cancer that is diagnosed at an early stage is more likely to have better outcomes. In young people this is especially important to consider because evidence suggests that they will have a more prolonged route to diagnosis than adults. They are also more likely to be diagnosed through emergency presentation than adults. If cancer spreads, effective treatment becomes increasingly difficult, and generally a person's chances of surviving are much lower. Yet the evidence suggests that patients in England are often diagnosed with cancer at a later stage than patients in comparable countries^v. Guidance on health education can help to address this imbalance.

Reducing time to diagnosis is a national policy priority in the existing Cancer Strategy, as well as for the upcoming long term plan for the NHS, as outlined by the Prime Minister in her October 2018 address.^{vi} In 2018, the APPG for Children, Teenagers and Young Adults with Cancer inquiry into patient experience found that 73% of young people and parents felt that not enough was being done to improve experiences of diagnosis. Having cancer education as a specific strand within health education is an opportunity for Government to equip young people with vital information, that could lead to early diagnosis of cancer and save lives. Teenage Cancer Trust's cancer education programme is an effective blueprint for how this should look, with research showing that 93% of young people who have attended a presentation said their knowledge and understanding of the warning signs of cancer increased as a result.

Young people who have experienced cancer have told us that:

- "I had all the classic symptoms of osteosarcoma, but I did not realise that this could be cancer...my symptoms went on for over 6 weeks with no cause, and this should ring alarm bells with everyone. Children need to be taught this."^{vii}
- "Before I was diagnosed I was having really bad headaches and was constantly tired but I didn't think anything of it. But when we went to the doctors we were shocked and surprised that tiredness was even a symptom to show you may have cancer. So I think sharing awareness is important so other people will know when something may not be right."^{viii}

A key part of Teenage Cancer Trust's Education and Awareness programme is giving young people confidence to go to the doctors to discuss their health, and the guidance on health education should contain this. 67% of young people who attend a Teenage Cancer Trust cancer education presentation agreed they were more confident about visiting a doctor or nurse to talk about their health^{ix}.

Teenage Cancer Trust would also highlight that current guidance is inadequate when considering the correlation between cancer in young people and their mental wellbeing. As the Government acknowledged in the recent Green Paper on 'Transforming children and young people's mental health' - 12% of young people live with a long-term condition,^x and the very presence of a chronic condition increases the risk of mental health problems from two-six times (Central Nervous System disorders such as epilepsy increase risk up to six- fold).^{xi}

Where the guidance refers to mental wellbeing, it is insufficient for helping young people lead a healthy lifestyle because it does not consider this impact that physical health conditions, especially chronic conditions such as cancer, directly have on mental health. Teenage Cancer Trust has found that 8 in 10 young people with cancer found the mental health impact of a diagnosis as difficult as the physical side,^{xii}

79% of young people felt cancer had a serious impact on their emotional wellbeing^{xiii} and that 90% of young people experienced anxiety during their cancer treatment.^{xiv}

Teenage Cancer Trust is supportive of the content within the draft guidance on the importance of healthy lifestyles. In adulthood, 4 in 10 cancers have causes that can be prevented through healthy lifestyle choices. Raising awareness of this, as guidance suggests, should start early.

Again, Teenage Cancer Trust's Education and Awareness presentation is a blueprint for how cancer education in schools should look, and this includes on healthy living. Our programme has demonstrable impact - significantly increasing recognition of being overweight, sunburn, HPV infection, importance of physical activity, pain recognition, changes of mole appearance, and the negative effects of alcohol and smoking.

Importantly, teachers themselves are very confident of the importance and impact that cancer education can have and we have the PSHE Association's quality mark for our lesson plans. Following the delivery of our Understanding Cancer Together presentation in schools in 2016/2017, we surveyed 669 teachers from 556 schools^{xv}:

- 98% strongly agreed or agreed that every young person should be taught about cancer before the age of 18, whilst
- 99% strongly agreed or agreed that it's important to work with an external provider to deliver cancer awareness in schools

Cancer is the biggest killer of young people by disease and informing young people about cancer simply cannot be limited to detailing how to live a healthy lifestyle, in order to help prevent certain types of cancer in adulthood. There must be a specific section in guidance on health education to enable understanding of the types of cancer that typically affect young people and an ability to recognise signs and symptoms (which could lead to early diagnosis). It should also consider the wider effects that a cancer diagnosis can have on an individual's mental health, ability to form relationships and to get back on track after cancer.

ⁱ Teenage Cancer Trust Mates Matter Survey 2017-2018

ⁱⁱ Ibid

ⁱⁱⁱ Patterson P et al (2017) Levels of unmet needs and distress amongst adolescents and young adults (AYAs) impacted by familial cancer *Psycho-Oncology* 2017;26:1285–1292.

^{iv} Opinion Leaders 'Impact and Outcomes' for Teenage Cancer Trust 2016-17

^v Capacity to diagnose? An analysis of cancer diagnostic activity in England (2018) Cancer Research UK

^{vi} Achieving world class cancer outcomes: A strategy for England

^{vii} Teenage Cancer Trust General Survey 2018

^{viii} Ibid

^{ix} Opinion Leaders 'Impact and Outcomes' for Teenage Cancer Trust 2016-17

^x Sawyer et al 2007

^{xi} Parry-Langdon, 2008; Taylor, Heyman & Goodman 2003

^{xii} <https://www.teenagecancertrust.org/channel-4-news-and-teenage-cancer-trust-special-report-mental-health-among-teens-and-young-people>

^{xiii} Clic Sargent (2017) Hidden Costs

^{xiv} Ibid

^{xv} Teenage Cancer Trust Understanding Cancer Together survey 2016/17