



Department
for Education

Consultation Response Form

Consultation closing date: 14 March 2014
Your comments must reach us by that date

Supporting pupils at school with medical conditions

If you would prefer to respond online to this consultation please use the following link: <https://www.education.gov.uk/consultations>

Information provided in response to this consultation, including personal information, may be subject to publication or disclosure in accordance with the access to information regimes, primarily the Freedom of Information Act 2000 and the Data Protection Act 1998.

If you want all, or any part, of your response to be treated as confidential, please explain why you consider it to be confidential.

If a request for disclosure of the information you have provided is received, your explanation about why you consider it to be confidential will be taken into account, but no assurance can be given that confidentiality can be maintained. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

The Department will process your personal data (name and address and any other identifying material) in accordance with the Data Protection Act 1998, and in the majority of circumstances, this will mean that your personal data will not be disclosed to third parties.

Please tick if you want us to keep your response confidential.	<input type="checkbox"/>
Reason for confidentiality:	

Name: Caroline Brocklehurst	
Please tick if you are responding on behalf of your organisation.	<input checked="" type="checkbox"/>
Name of Organisation (if applicable): Teenage Cancer Trust	
Address: 3 rd Floor 93 Newman Street London W1T 3EZ	

If your enquiry is related to the DfE e-consultation website or the consultation process in general, you can contact the Ministerial and Public Communications Division by e-mail: consultation.unit@education.gsi.gov.uk or by telephone: 0370 000 2288 or via the Department's ['Contact Us'](#) page.

Please mark the box that best describes you as a respondent.

<input type="checkbox"/>	Headteacher/Principal	<input type="checkbox"/>	Teacher	<input type="checkbox"/>	Governor/chair of governors
<input type="checkbox"/>	Local authority	<input type="checkbox"/>	Pupil	<input type="checkbox"/>	Parent/carer
<input type="checkbox"/>	Union/representative body	<input type="checkbox"/>	Professional association	<input checked="" type="checkbox"/>	Other

Please Specify:

Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and outcomes for young people with cancer. 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. And through our own research and working with our partners in the NHS, across the UK governments, and organisations both nationally and internationally, we strive to improve outcomes for young people.

Registered charity: 1062559

The introductory section of the guidance sets out the purpose of the new duty, and provides an overview of some of the key issues.

1 Does the introduction section set out effectively the purpose of the guidance and explain why intervention is needed?

<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No	<input type="checkbox"/> Not Sure
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Comments:

We feel that the introduction to the guidance would be strengthened by including a broad definition of what is meant by 'medical conditions'. Much of the content of the guidance within the consultation document relates to lifelong, chronic conditions. While recognising the importance of providing appropriate support and provision to these children and young people, we feel it is equally important to have regard for the circumstances of young people receiving diagnoses of acute conditions such as cancer. We strongly welcome the confirmation given by Lord Nash in October 2013 that this guidance will be statutory in relation to young people with cancer¹, over and above their rights as disabled people under the Equality Act 2010, and feel it is important that this obligation is clearly recognised within the guidance as a result.

Furthermore, while some young people with cancer will return to school while continuing with treatment, others may complete their treatment and return to school once in remission. For these young people their need for additional support in schools does not end once they have completed their treatment. It would be helpful for the introduction to highlight that those children who have had, or who are recovering from, medical conditions will also need a similar level of support as those whose condition is ongoing. Point three of the guidance currently offers scope for support to be withdrawn to pupils at this stage. For example, for young people returning to school following cancer treatment ongoing cognitive effects can include a reduction in memory, information retention and organisational ability. Physical consequences might include amputation and chronic, on-going fatigue. While some of these effects are immediately visible to teachers and other pupils, others, such as fatigue, are less visible or less well known, and all are likely to require additional support long after treatment for cancer may have concluded.

Point four of the introduction highlights that some children with medical conditions may be disabled. We welcome the inclusion of the duties on governing bodies for these pupils, as cancer is a specifically defined disability under the Equality Act 2010, yet we know that many young people, their families and their schools are not aware of this status, or its implications on their entitlement to support. It would be helpful, therefore, to include in this section those conditions that have protected characteristics, such as cancer. This will help young people with cancer, their families, and the numerous

¹ HL Deb 23 October 2013, c393GC

health and education professionals who will have regard to the guidance to identify that this document is applicable to them.

Role of the governing body

2 Is the guidance clear about what issues governing bodies will be expected to consider in making those arrangements and in ensuring that schools develop and implement managing medicines policies?

Yes

No

Not Sure

Comments:

School policies

3 Does the suggested content cover the minimum that is required for good practice?

Yes

No

Not Sure

Comments:

Point 12: We welcome the proposed two week target for setting out support procedures for young people with a new diagnosis. Teenagers, young adults and parents, when facing a cancer diagnosis, will benefit from the speedy provision of support. In order for these timelines to be met it will be important for young people and their parents to be aware of what support they are entitled to, for health and education professionals to understand that cancer is included as a medical condition for which this support must be provided, and for sufficient numbers of school nurses and other staff to be available to develop and implement such arrangements. It is unclear from the guidance whether data will be collected on the time from a governing body being notified of a pupil's medical condition to the time arrangements are put in place, however we would recommend that this data is collected and publicly reported on in order to highlight any regional variations.

Individual healthcare plans

4 a) Is the guidance clear that decisions about the support to be provided to pupils with medical conditions should be based on the individual needs of each child, on a case by case basis?

Yes

No

Not Sure

Comments:

Point 13: We support the rationale of individually tailoring individual healthcare plans to reflect the complexity of a pupil's condition and the degree of support required. However, we have concerns regarding the statement that 'not all children will require one'. In order to ensure that governing bodies meet their statutory duties under this legislation it may be useful to set out a threshold over which individual healthcare plans become a requirement.

Point 14: It is vital that the link between individual healthcare plans and EHC plans is explained in more detail than currently exists in the guidance.

4 b) Is the guidance clear about the use of individual healthcare plans, how these are developed and what they should contain?

Yes

No

Not Sure

Comments:

4 c) The name, 'individual healthcare plan (IHCP)' is very close to SEN Education, Health and Care (EHC) plans. To what extent do you believe this will be confusing in practice?

<input checked="" type="checkbox"/>	Very confusing	<input type="checkbox"/>	Confusing	<input type="checkbox"/>	Slightly confusing
<input type="checkbox"/>	Not at all confusing				

Comments:

A wide range of stakeholders will be involved in the instigation, design and implementation of individual healthcare plans, while many of the same and numerous others will be involved in EHC plans. These stakeholders include health and education professionals, parents and young people themselves, who will all have varying levels of knowledge and expertise. As a result it will be key to make sufficient information, in accessible forms, about the relationship between the two plans available to remove as much potential confusion as possible.

Furthermore, the Children and Families Bill and SEN Code of Practice must make reference to individual healthcare plans, while this guidance would benefit from more cross referencing with EHC plans and their associated legislation.

Roles and responsibilities

5 Is the guidance clear about the need for co-operation and collaborative working arrangements between relevant health services, schools, parents and pupils and provide sufficient information about roles and responsibilities?

Yes

No

Not Sure

Comments:

Staff training and support

6 Is the guidance clear about the need for staff to be appropriately trained and who is responsible for identifying and providing that training?

Yes

No

Not Sure

Comments:

Managing medicines - including children's role and record keeping

7 Is the guidance clear on how medicines should be managed in school?

Yes

No

Not Sure

Comments:

Emergency situations

8 Is the guidance clear that schools need to have procedures in place for dealing with emergency situations?

Yes

No

Not Sure

Comments:

Day trips, residential visits and sporting activities

9 Is the guidance clear that pupils with medical conditions should be actively included in and not be prevented from participating in such activities?

Yes No Not Sure

Comments:

Unacceptable practice

10 Is the guidance clear about unacceptable practices?

Yes No Not Sure

Comments:

Liability and indemnity

11 Is the guidance clear about what needs to be done in relation to insurance arrangements?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not Sure
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Comments:

Complaints

12 Is the guidance clear about what parents should do if they wish to make a complaint?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not Sure
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Comments:

Further sources of information

13 Does this section provide sufficient information about the broader legislative framework and the further information, advice and guidance, and other resources to be provided on-line?

Yes

No

Not Sure

Comments:

The role of Local Authorities in providing re-integration plans for children who are absent from school because of health needs is laid out in the Education Act 1996 and associated statutory guidance², and we recommend that this is included as a separate point alongside their responsibilities regarding alternative provision arising from this Act.

² Department for Education (2013), *Ensuring a good education for children who cannot attend school because of health needs: Statutory guidance for local authorities*

A flowchart has been provided that sets out the process that may be followed for identifying and agreeing the support a child needs, and is intended to help the development and implementation of individual healthcare plans.

14 To what extent do you think the flowchart will be helpful in supporting the process of developing and implementing individual healthcare plans?

<input type="checkbox"/>	Very helpful	<input checked="" type="checkbox"/>	Helpful	<input type="checkbox"/>	Not very helpful
<input type="checkbox"/>	Not at all helpful				

Comments:

It may be useful to expand the flowchart to include where EHC plans would be instigated and come into effect, in the same way as has been done for individual healthcare plans.

15 Overall, how helpful do you feel the statutory guidance will be in helping governing bodies to put in place arrangements for supporting pupils with medical conditions effectively?

<input type="checkbox"/>	Very helpful	<input type="checkbox"/>	Helpful	<input checked="" type="checkbox"/>	Not very helpful
<input type="checkbox"/>	Not at all helpful				

Comments:

Cancer, its treatments and late effects can have a huge impact on a young person's experience of education. Seven young people aged between 13 and 24 are diagnosed with cancer every day in the UK, that's around 2,500 new cases each year. 80% of teenagers and young adults with cancer now survive for five years or more, and so the numbers seeking to return to or remain in education are only set to increase³. It is therefore vital that young people with cancer have access to appropriate support within education at the time of their diagnosis, during their treatment, and post-treatment.

We have been supporting and advocating for young people with cancer for over 20 years, and, as world leaders in the field of teenage and young adult cancer care, we welcome the opportunity to comment on this consultation. We welcome many elements, particularly the recognition of the importance of including children and young people in making decisions on the support they will receive, and the holistic nature of individual healthcare plans which recognise the impact of medical conditions on the psychosocial wellbeing of young people. However, we feel that changes must be made to the guidance, in line with all of our feedback above and submissions made by others within the wider charitable and voluntary sector, to guarantee that consistent and sufficient support will be put in place.

When responding to the Department's consultation on the SEN Code of Practice we expressed concern that the current Children and Families Bill, and the resulting Code of Practice, were such that the large numbers of young people with cancer who are not entitled to SEN provision will be outside of the scope of the additional support provided by EHC plans. Within this new guidance we remain concerned that the absence of a definition of a medical condition to include cancer, the limitations to its statutory elements, the lack of a threshold for individual healthcare plans, and the potential for confusion between different plans, mean that young people with cancer remain at risk of slipping through the net and missing out on the vital support to which they are entitled.

³ Cancer Research UK (2013), *Cancer Stats Report: Teenage and young adult cancer*

Thank you for taking the time to let us have your views. We do not intend to acknowledge individual responses unless you place an 'X' in the box below.

Please acknowledge this reply.	
E-mail address for acknowledgement:	

Here at the Department for Education we carry out our research on many different topics and consultations. As your views are valuable to us, please confirm below if you would be willing to be contacted again from time to time either for research or to send through consultation documents?

<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
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All DfE public consultations are required to meet the Cabinet Office [Principles on Consultation](#)

The key Consultation Principles are:

- departments will follow a range of timescales rather than defaulting to a 12-week period, particularly where extensive engagement has occurred before
- departments will need to give more thought to how they engage with and use real discussion with affected parties and experts as well as the expertise of civil service learning to make well informed decisions
- departments should explain what responses they have received and how these have been used in formulating policy
- consultation should be 'digital by default', but other forms should be used where these are needed to reach the groups affected by a policy
- the principles of the Compact between government and the voluntary and community sector will continue to be respected.

However, if you have any comments on how DfE consultations are conducted, please contact Carole Edge, DfE Consultation Coordinator, tel: 0370 000 2288 / email: carole.edge@education.gsi.gov.uk

Thank you for taking time to respond to this consultation.

Completed responses should be sent to the address shown below by 14 March 2014

Send by post to:
Department for Education
School staffing policy and reducing bureaucracy team

Teachers Group
4th Floor, Sanctuary Buildings
Great Smith Street
London
SW1P 3BJ

Send by e-mail to: MedicalConditions.CONULTATION@education.gsi.gov.uk