

## **Guidance for school when supporting children/young people with brain tumours**

Dr Vicky Ringer our education specialist carried out a recent study focusing on supporting CBTS upon return to school. The study reported on the importance of school staff recognising the enormity of a childhood brain tumour diagnosis, the impact a brain tumour has on the lives of child/young person and parents/carers and how a close level of home-school communication and collaboration is an essential part of helping school understand and support the child's initial and ongoing needs. Indeed, a positive relationship between school and parents/carers can help support CBTS to make progress at school, access and experience the fullness of school life, and reach their full potential.

The full study can be accessed here:

[https://etheses.whiterose.ac.uk/id/eprint/34684/1/VR%20Thesis%20Final%20Feb%202024%20\(1\).pdf](https://etheses.whiterose.ac.uk/id/eprint/34684/1/VR%20Thesis%20Final%20Feb%202024%20(1).pdf) but **key findings and practical guidance for schools and parents/carers are summarised below:**

### **1. When a child/young person is initially diagnosed with a brain tumour:**

- Early and ongoing communication between school and parents of childhood brain tumour survivors (CBTS) is essential when a child is diagnosed with a brain tumour.
- Parents should contact the school Headteacher or/and school SENCO when their child is diagnosed with a brain tumour. The Headteacher should inform the school SENCO, if parents have not managed to do so.

### **2. Throughout the child/young person's brain tumour treatment:**

- School should stay in touch with child/young person and parents/carers throughout the child's brain tumour treatment. This could include the SENCO, class teacher and TA sending cards and messages from staff and peers to the child and keeping lines of communication between school and parents/carers open. Remember, it can be isolating for children/young people

who are absent from school due to going through brain tumour treatment and so staying in touch can help them feel part of school. Communicating with parents/carers also lets them know that you care about their child and are there to help.

- The school SENCO (in collaboration with the class teacher/subject teachers) could communicate closely with the hospital teacher in order to send appropriate schoolwork for the child. This is especially important considering CBTS may be absent from school for a considerable length of time.
- Staying in contact with parents/carers of CBTS will help the SENCO understand how the child's treatment is going and know when to start arranging multidisciplinary meetings to support the child/young person's return to school.

### 3. Preparing for child/young person's return to school:

Early and ongoing communication between school, parents/carers, CBTS, HCPs and external professionals is a vital part of ensuring a package of appropriate support is in place for the child/young person **from day 1 of their return.**

- School should be aware that treatment for a childhood brain tumour may be life threatening and life changing and could include treatment such as brain surgery to debulk/remove the tumour, chemotherapy, radiotherapy and proton therapy. As result of the tumour and treatment, the child may experience physical and cognitive difficulties as well as social and emotional challenges that they did not have prior to treatment. In essence they may return to school a different child to the one they were prior to diagnosis.
- **It is essential** for the SENCO to arrange timely multidisciplinary meetings to help school identify the child's initial and ongoing support needs. Support meetings are likely to include the child/young person's parents/carers, the school SENCO, class teacher (if the child is at primary school), Head of Year (if at secondary school), any allocated teaching assistants (TAs) who will be supporting the child/young person, neuro oncology nurse, school nurse, EP, OT, SaLT, hospital teacher, Levi's Star specialist assessor and any other

professional providing support for the child. Be aware that TAs provide valuable daily support for CBTS and need to be included in all support meetings and parents are keen for this to happen.

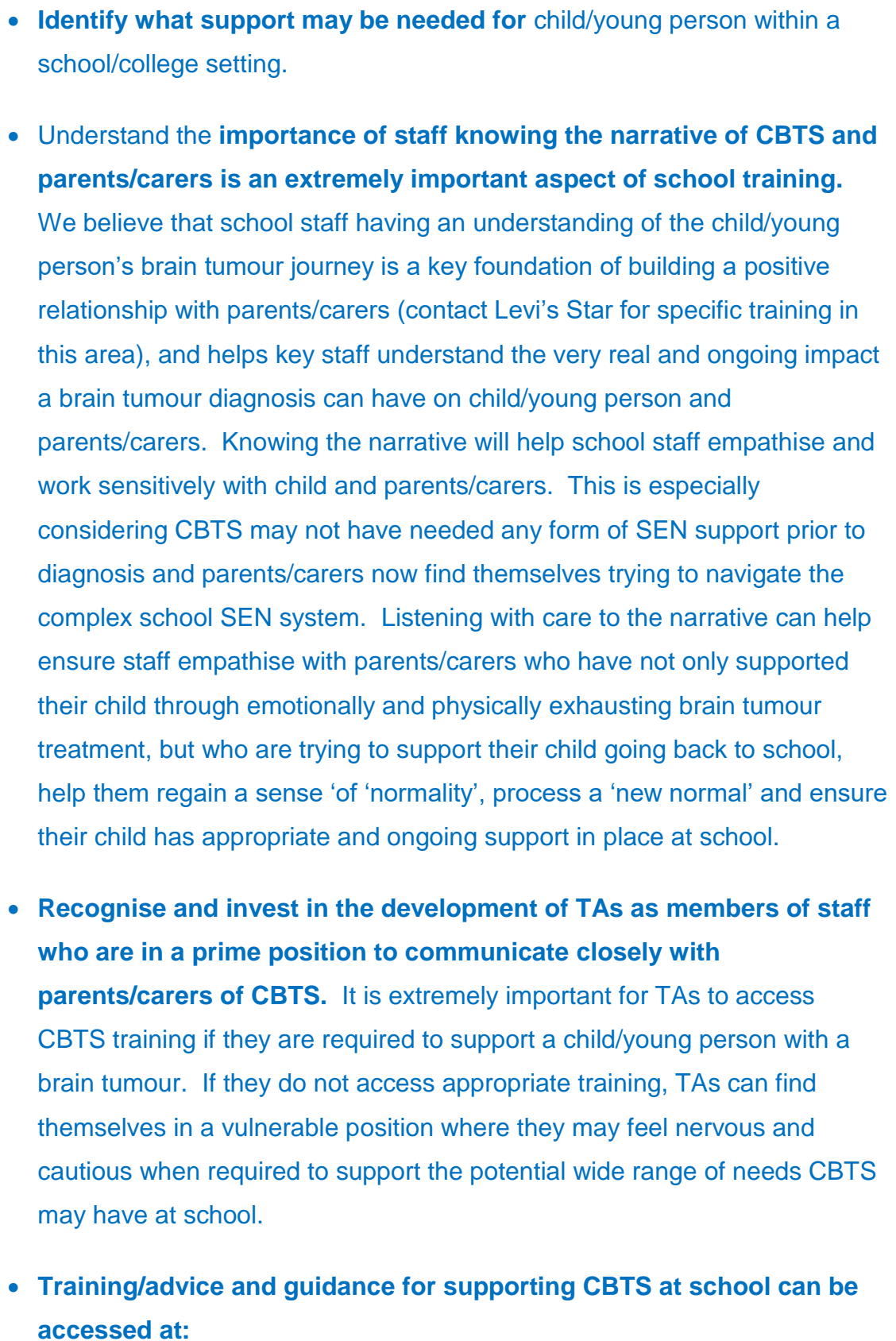
- **To understand the child/young person's learning profile and the level of support and intervention they may need upon return to school, contact Levi's Star Children's Brain Tumour Charity Educational Outreach Service.** Dr Vicky Ringer is a teacher and specialist assessor who can assess the child/young person's literacy and cognitive processing skills in order to inform the level of support they need within the classroom, any exam access arrangement concessions and specific intervention. Practical strategies for support and intervention will be guided by Levi's Star as part of a report written for the child/young person, based on their learning profile (as part of the educational assessment). Be aware this assessment is not instead of a hospital neuropsychological assessment, but in addition to and is especially helpful if the child/young person hasn't had a neuropsychological assessment by the time they return to school. It is also useful to know as education specialists with a background in teaching, our recommendations are very much geared toward the classroom.

In addition, outcomes of our assessments can be used to provide school with additional evidence of the child's needs if they are applying for an EHCP for the child. **However, whether an EHCP is applied for or not, understanding the range of needs of all CBTS, well in advance of their return to school, allows school adequate time to develop support plans before the child returns to school.**

- **Make sure staff access appropriate training to understand the needs of CBTS, before the child/young person returns to school/education.**

**Training should help staff:**

- Understand how having a **childhood brain tumour can result in an acquired brain injury (ABI) long-term in nature, and develop awareness of what this can mean for the child/young person within education.**

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- **Identify what support may be needed for child/young person within a school/college setting.**
  - **Understand the importance of staff knowing the narrative of CBTS and parents/carers is an extremely important aspect of school training.** We believe that school staff having an understanding of the child/young person's brain tumour journey is a key foundation of building a positive relationship with parents/carers (contact Levi's Star for specific training in this area), and helps key staff understand the very real and ongoing impact a brain tumour diagnosis can have on child/young person and parents/carers. Knowing the narrative will help school staff empathise and work sensitively with child and parents/carers. This is especially considering CBTS may not have needed any form of SEN support prior to diagnosis and parents/carers now find themselves trying to navigate the complex school SEN system. Listening with care to the narrative can help ensure staff empathise with parents/carers who have not only supported their child through emotionally and physically exhausting brain tumour treatment, but who are trying to support their child going back to school, help them regain a sense 'of 'normality', process a 'new normal' and ensure their child has appropriate and ongoing support in place at school.
  - **Recognise and invest in the development of TAs as members of staff who are in a prime position to communicate closely with parents/carers of CBTS.** It is extremely important for TAs to access CBTS training if they are required to support a child/young person with a brain tumour. If they do not access appropriate training, TAs can find themselves in a vulnerable position where they may feel nervous and cautious when required to support the potential wide range of needs CBTS may have at school.
  - **Training/advice and guidance for supporting CBTS at school can be accessed at:**

Levi's Star Children's Brain Tumour Charity (offers training, guidance and educational assessments and access testing) [www.levisstar.co.uk](http://www.levisstar.co.uk) contact Dr Vicky Ringer 07971932610

The Child Brain Injury Trust <https://www.childbraininjurytrust.org.uk>

The Royal Marsden NHS Foundation Trust (2019) Guide to Supporting Children with Cancer at School <https://patientinfolibrary.royalmarsden.nhs.uk>

The Brain Tumour Charity [www.thebraintumourcharity.org](http://www.thebraintumourcharity.org)

The Sam White Pathway (2017) Making a Successful Return to Education: Supporting Children and Young People with Acquired Brain Injuries (ABI)

International Paediatric Brain Injury Society <https://www.ipbis.org>

- **In preparing for the child/young person's return to school, the SENCO should talk to parents of CBTS about what information they are happy for you to share with school staff, their child's peers and other parents, regarding their child's diagnosis.** For example, some parents may be happy for you to talk to all staff regarding their child's brain tumour journey, other parents may have a desire to speak directly to school staff themselves. Some parents may also have a desire for school to raise awareness about brain tumours and will want to arrange charitable events. It really is an individual journey for each family and must be discussed with parents/carers with a high level of sensitivity. The school SENCO should also carefully consider how to support the child's school peers when CBTS return to school. It may be helpful to ask the child's neuro oncology nurse to speak to the child's peers to explain what happened to their peer and to answer any questions/worries they may have.
- **Consider supporting the child's return to school by arranging an initial and gentle 'welcome back day', where the child (and parent/carer where appropriate) visit school for a few hours initially, and make sure all staff are aware of the child's support needs from this very first step back into school. CBTS may also need a part time timetable when they return to school,**

especially if they suffer from fatigue. **Make no mistake, CBTS are likely to have been through a frightening and exhausting brain tumour journey and even though they may be looking forward to seeing their friends and returning to 'normal', life may now be different for them. Deal with child/young person and parents/carers with sensitivity and care. Reassure parents that appropriate support is in place at school, and their child will be understood, supported, safe and cared for by school staff.**

- **Daily communication between school and home** is likely to be needed initially through channels such as a home/school diary, one to one conversation with parents/carers at drop off and pick up, and/or telephone calls home. The level of communication with parents will probably vary over time but regular contact helps reassure parents that their child is being supported and their needs are being met. Working closely with parents will also help school staff understand the child's needs more fully, recognising that parents know their child best.
- **Having a key point of contact at school is recommended for parents/carer.** This may for example be the SENCO, deputy SENCO, teacher, Head of Year – someone who knows the child/young person well and is in a position to build a strong, positive and caring relationship with parents and child.
- If needed and depending on the child's support needs, apply for an EHCP in good time. Also make sure support plans are in place for CBTS who do not require an EHCP. CBTS need to be appropriately supported from day one of their return. **Be aware, although not all children with brain tumours will have or need an EHCP in place they may still need ongoing support and a support plan in place.**
- **Understand where school support for CBTS sits within the SEN Code of Practice but also consider creating a support policy for children with brain tumours (and ABI). This will provide more specific guidance as**

SEN guidance alone is arguably not specific enough to meet the unique needs of CBTS.

- **Does your school have a school and parent partnership policy in place?** Schools may have a general home-school agreement in place, but no home-school partnership policy. You may wish to create one. **Implementation of CBTS school policy and a school – parent partnership policy**, will help guide school staff about the complexities involved in supporting CBTS and working collaboratively with parents/carers.

*Be mindful when schools have a strong level of preparedness and training in place to support the range of needs of CBTS, parents feel re-assured and confident that their child will be safe at school, supported appropriately, understood and cared for throughout their educational trajectory.*

#### **4. Supporting CBTS throughout their educational journey**

- **As CBTS progress through key stages in their education and develop skills, their support needs may change.** Working in partnership with parents of CBTS, communicating regularly with them and listening to the child's views will help staff track and monitor progress and identify and adapt to any changing **visible and invisible needs of CBTS**. For example, the level of physical support may lessen for some CBTS, but they may continue to struggle with short-term memory and speed of processing and experience social difficulties. Update the child's support plan or EHCP accordingly.
- **Support staff may find it challenging to find a balance between supporting CBTS and keeping them physically safe at school and allowing a level of independence the child/young person craves.** Listening to the voice of CBTS and parents/carers regarding what support is working well for the child/young person or not, will help you adapt the level of support. Collaborating closely with parents/carers, child and external support (eg OT, physio), will help teachers and support staff get the balance right. Indeed, parents/carers and school should work closely to facilitate small steps of independence for CBTS in the classroom and in the wider school setting,

recognising a growing level of independence is important to and for CBTS in the present and the future. School should address any support problems as they arise and safely adjust support as needed. Honesty, transparency and trust are a foundation of developing a positive home and school relationship.

- **Carefully track and monitor the progress of CBTS and celebrate small steps of success with child/young person and parent/carers.** Indeed, parents/carers appreciate knowing about small steps of progress their child is making, as parents are not there during the school day to see these small but important triumphs! **Likewise, parents/carers of CBTS please communicate positive feedback regarding your child's school support to school staff.** This can help boost the morale of staff working hard to meet the needs of CBTS.
- **Ensure relevant access arrangements are in place for CBTS throughout all key stages** (Levi's Star can officially assess and re-assess students for this for free, to inform exam concessions for SATs, GCSEs, A Level and beyond). Dr Vicky Ringer is a qualified dyslexia assessor and as such is qualified to carry out official access arrangement testing. This may be especially helpful if CBTS do not have an EHCP in place.
- **Arranging ongoing training for school staff will ensure they are updated regarding the child's progress and changing areas of need.** How to share the ongoing narrative of CBTS should be carefully discussed with parents/carers. Ongoing training will ensure new staff are aware of the child/young person's brain tumour narrative and support needs, and existing staff are reminded. Also be mindful of if/what CBTS are happy for you to share with their peers regarding their brain tumour diagnosis as they progress through education.

**Building a positive home-school relationship is a foundation of ensuring CBTS are not only safe at school but are supported to develop a level of independence needed for quality of survivorship.**

Key findings of our research highlighted a need for key school staff to have access to a visual pathway of support guiding support for children living with the effects of a brain tumour which we have summarised as below:

## SCHOOL PATHWAY OF SUPPORT FOR CHILDREN WITH BRAIN TUMOURS

### ON DIAGNOSIS

- ★ When school are informed a child has been diagnosed with a brain tumour ensure the SENCO is notified immediately.
- ★ SENCO should contact parents, reassuring them you are there to help support them and child. Remember this is likely to be a frightening and physically and emotionally challenging time for child and parents.
- ★ SENCO and relevant key school staff keep channels of communication with parents open during child's absence from school. For example, communicate with parents to understand the child's progress and send cards/emails from classmates and staff to the child to ensure they still feel a valued and included member of school.
- ★ SENCO speak to the hospital teacher and consider if work needs to be sent home/to the hospital for your student during their absence.

### PREPARING FOR A CHILD'S RETURN TO SCHOOL

- ★ Contact Levi's Star Children's Brain Tumour Charity Education Outreach Service if you would like your student to access an educational assessment. This will help identify the child's literacy, cognitive processing and social needs and inform support, intervention, and exam concessions. Be aware brain tumours are classed as acquired brain injuries (ABI).
- ★ SENCO should arrange multi-agency meetings with parents well in advance of child's return to school and invite relevant professionals e.g. hospital neuro oncology nurses, school nurse, SALT, physio, OT, EP, Levi's Star specialist teacher, class teacher and TA. This will help you understand the child's physical, medical, cognitive, social, emotional and educational support needs.
- ★ Taking time to listen with care, generosity, and empathy to the ongoing narrative of the child and parents brain tumour journey should be high on your radar. This will help you to work closely and sensitively with parents and child.

- ★ Remember to arrange pre-school visits for child and parents in preparation for the child's return to school and consider what to tell other children and parents. Work closely with parents to decide if, how or when this could be done.
- ★ Be aware, although not all childhood brain tumour survivors (CBTS) will require an EHCP upon return to school, ALL need to have an appropriate level of support in place from day 1 of their return.
- ★ Ensure your staff have accessed relevant training around supporting children with brain tumours/ABI, ideally before the child returns to school (contact Levi's Star for more information).

### THROUGHOUT A CHILD'S EDUCATION...

- ★ Provide CBTS/ABI training for new staff or staff new to teaching the student, along with updated training for staff. Keep sharing the changing narrative of child and parents.

- ★ Ensure all key staff are aware of child's ongoing and changing support needs, including 'invisible needs' such as speed of processing and short-term memory difficulties.

- ★ Celebrate small steps of progress, closely track and monitor the child's support needs, and adjust support as appropriate - this works best when done in partnership with parents and child.

**Levi's Star**  
Children's Brain Tumour Charity

Don't forget to contact Levi's Star if you would like to discuss training or your student to have an updated educational assessment at any point in their education.

For more information or to access Levi's Star Children's Brain Tumour Educational Outreach Service, please contact Dr Vicky Ringer at [levisstar@btinternet.com](mailto:levisstar@btinternet.com) [www.levisstar.co.uk](http://www.levisstar.co.uk) Tel 07971 932610

### WORKING IN PARTNERSHIP WITH PARENTS

- ★ Providing a key point of school contact for parents of CBTS works well.
- ★ Building a close, two-way and honest relationship with parents helps ensure the child's ongoing and changing needs are identified, recognised and met, and reassures parents their child is safe, understood and cared for in school.
- ★ Working in partnership with parents of CBTS helps school staff understand the changing needs of CBTS, facilitating a balance between supporting the child and encouraging their independence.

## When?

We offer education support and advice to children and young adults who are receiving, or have completed, treatment for a brain tumour. There is no time limit to the support offered, as we are committed to identifying the level of support needed for the children & young people, living with the effects of a brain tumour.

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## **Where and How?**

We work with children, young people, and schools/colleges across Yorkshire. Contact Dr Vicky Ringer, our specialist teacher and leader of the education outreach service. We assess from our centre in Garforth, Leeds. We welcome referrals from other hospitals, social workers, GPs, schools and self-referrals. In short, anyone who has the permission of the parent or carer can refer to us. Please contact Dr Vicky Ringer, Children and Young People’s Brain Tumour Education Outreach Specialist, for more information about this service on:

**Dr Vicky Ringer – Specialist SEN Teacher and Service Leader,  
supporting 5-25 yrs**

**[07971 932610](tel:07971932610) or email [levisstar@btinternet.com](mailto:levisstar@btinternet.com)**