

Making a Successful Return to Education: Supporting Children and Young People with Acquired Brain Injuries (ABI)

This guidance document is the result of the collaboration between Dr Nicki Hammill (Educational Psychology Service), with Dr Emily Bennett (Clinical Psychologist, Department of Paediatric Neuropsychology, Nottingham University Hospitals NHS Trust) and Pam White (parent).

This document draws on our experience of accompanying Sam White on his educational journey, as he returned to school following his treatment for a brain tumour. His experience provided invaluable learning about what should be considered good practice around preparing for a child or young person's return to school post-ABI. He was an inspiration to those who were lucky enough to have known or worked with him. Therefore, this document is dedicated in his memory as a legacy of his strength and determination that others should benefit from his experience.

Sam had planned to contribute to this guidance and his mum, Pam, represents his perspective with her notes on 'Sam's journey', which are included within this guidance.

1. Introduction

The purpose of this guidance is to help schools understand how best to support children and young people (CYP) who have an acquired brain injury (ABI). An ABI is any injury which has occurred to the brain after birth. Such injuries can be the result of (i) unanticipated medical events, e.g. brain haemorrhage, (ii) illnesses, e.g. cancer (iii) infections, such as meningitis (iv) accidental injuries, e.g. road traffic accidents or (v) non-accidental injuries, e.g. assault. The outcomes from an ABI are extremely varied, and can range from mild to severe. In more severe cases, a CYP may be significantly different to their pre-ABI self. Careful consideration is required, therefore, not just of their physical and cognitive requirements, but also of the impact of their ABI on their social and emotional needs.

This guidance offers advice on how to manage a child or young person's return to school after an ABI. The document also addresses managing ABI resulting from cancer, which introduces additional factors requiring consideration (*recommendations specifically in relation to cancer related ABI are noted in italics*).

This guidance should be read alongside the many existing resources available to schools (see signposting section at end of document). This document is designed to support the CYP's returning to school within the county of Nottinghamshire.

1a. The impact of an acquired brain injury

According to the Child Brain Injury Trust (2014), one young person acquires a brain injury every 30 seconds in the UK. The consequences of such brain damage are often far-reaching, and can impact on a young person’s functioning across physical, behavioural, cognitive, social and emotional domains.

Just as the causes of brain injuries are variable, so are the outcomes for each individual CYP. Some of the key difficulties a CYP may experience post-brain injury are listed below. Importantly, while some CYP may make good recoveries in several or all areas, others will have long-term and even lifelong difficulties.

Table 1. Key areas of difficulty after brain injury

General effects	Cognitive effects	Physical effects	Behavioural and emotional effects
<ul style="list-style-type: none"> • Fatigue – cognitive & physical • Pain • Sleep problems 	<ul style="list-style-type: none"> • Memory • Processing speed • Learning • Attention • Executive function • Language & communication 	<ul style="list-style-type: none"> • Problems with movement, coordination and / or speech • Visual difficulties • Hearing difficulties 	<ul style="list-style-type: none"> • Changes in behaviour • Anxiety, low mood, anger etc • Problems with self-esteem

In many cases, an ABI results not just in an injury to a specific part of the brain, but also in disruption to the wider pathways. Post-injury, therefore, the brain needs time to heal and may also have to find new ways of doing things, or new routes to pass information through. This can make the brain slower and less efficient. It also uses a lot of energy, and can make the person with the injury extremely tired.

Some brain injuries can be widespread and affect several parts of the brain (so called ‘diffuse’ injuries), or they can affect a very specific part of the brain (e.g. a tumour in a particular location). As the parts of the brain work closely together, there are likely to be a number of difficulties resulting from either type of injury. Some problems, such as fatigue, problems with emotions and attention, are common after any type of ABI, while others may be more specifically linked to the type and location of injury. It is important, therefore, to consider every CYP individually.

1b. Important points to remember

- Many of these difficulties are closely linked, and are likely to impact on other areas, e.g. pain and fatigue impact on attention and behaviour, as well as mood and learning
- Many disabilities are hidden and may be forgotten about as the CYP progresses through education. This can leave them vulnerable to being labelled with behavioural or motivational issues when, in fact, they are still struggling with the impact of their earlier brain injury
- Some CYP may make good recoveries in several or all areas, others will have long-term and even lifelong difficulties
- Some difficulties may not be present immediately after injury, but can emerge as the young person’s brain develops. This is why it is important that CYP are monitored throughout their educational pathway and not just in the immediate aftermath of an ABI
- After an ABI, some CYP may have limited insight or understanding of their difficulties which can present additional challenges for their adjustment, integration and progress

2. Engaging with learning whilst in hospital/transitioning to home

Children and young people living within Nottinghamshire will usually be treated at the Queens Medical Centre (QMC) in Nottingham. At the QMC, there is a dedicated team of educational professionals who will provide educational support to children and young people who are well enough to engage with learning during their stay in hospital.

Depending on the nature of the ABI, there may be a large number of professionals involved in a CYP's care. This may include psychologists, physiotherapists, occupational therapists, and medics, as well as neuro-rehabilitation services, such as the BRILL Team (Brain Injury Living Life). Initially, the team at the hospital will arrange meetings for the agencies involved to plan the appropriate next steps. This multi-disciplinary approach (MDA) ensures that health and educational professionals, as well as other services involved (e.g. Social Care) meet regularly to ensure the CYP receives all aspects of support required. It also ensures each agency is clear on their respective roles, remit and required actions. Once the child has been discharged from hospital, it is crucial that schools lead on continuing to convene multi-disciplinary meetings in preparation for school return and beyond.

Sam's journey: "Returning home proved to be quite a challenge. An appropriate school plan wasn't in place and the implications of the brain injury were simply not understood. Plus, although not the student who had left school all those weeks earlier, Sam needed to be back in that environment and let people realise what he needed. Not just his peers, but staff also. Here is where the real work began."

3. Transitioning home and back into school – planning ahead

3a. Role of the Neuropsychology Team

In light of the potential challenges for a CYP after ABI, they should receive a referral to see a neuropsychologist. The timing of the referral will be dependent on the nature of the ABI.

A neuropsychologist is a professional who specialises in understanding how the brain and its abilities are affected by injury or illness. Paediatric neuropsychologists focus on understanding why a young person may be having difficulties in school or at home. This is done by examining academic skills and all of the thinking skills needed to perform well in and outside of school – skills like memory, attention, and problem-solving. Neuropsychologists have training in clinical psychology so they are also able to explore the emotional consequences of an ABI, such as depression and anxiety.

The paediatric neuropsychologist assesses, interprets and makes recommendations based on their findings. A typical CYP neuropsychological assessment might consider the following areas:

- General intellect
- Learning, memory and attention
- Language
- Executive skills, such as organisation, planning, inhibition, and flexibility
- Visual-spatial skills
- Motor co-ordination
- Behavioural and emotional functioning
- Social skills

This will allow the neuropsychologist to comment on the following areas:

- How an ABI may relate to difficulties seen at school, home, or with peers
- How a CYP learns best
- How an ABI may impact on a CYP's behaviour, and how best to manage such behaviour
- How academic expectations can be matched to a CYP's specific strengths and weaknesses

The neuropsychologist will then make recommendations for supporting cognitive differences and any emotional/behavioural concerns. They may offer further targeted support or refer on other professionals. The neuropsychological assessment is an important tool in helping the CYP, their family and other professionals better understand the impact of their injury, and in helping them plan for the future. An understanding of a CYP's specific strengths and weaknesses is particularly essential when planning a successful return to education.

Sam's Journey: "The Neuropsychology report was such a valuable document, it presented school with so much information and meant we could talk to the Educational Psychologist about "the plan" with confidence. It also gave the Teaching Assistant (TA) something with which to work when planning Sam's timetable. Plus, it enabled the TA to access the appropriate level of training to address the issues displayed by the brain injury. But not only that, it was a massive help in completing the application for a Statement of Special Educational Needs (now known as an Education Health Care Plan)"

3b. Education and Health working together

Whilst a child or young person is in hospital, the team of health professionals involved should organise Discharge Planning Meetings (also known as Team Around the Child meetings) which school staff will be invited to attend. In light of the complex needs of many CYP with an ABI, it is important that health and education work closely together. Therefore, whilst the CYP is in hospital, it is crucial that a member of the staff from school remains actively involved and liaises with the health professionals as required.

3c. The role of the Health Related Education Team in returning to education

In Nottinghamshire, if educational provision is initially to be made within the CYP's home, the school should submit a request for support from the Health Related Education Team (HRET).

Statutory guidance clearly sets out a school's responsibility for CYP who are unable to attend school because of medical needs for more than 15 days (consecutively or cumulatively). The Department for Education states, all local authorities must "*arrange suitable full-time education (or as much education as the young person's health condition allows) for children of compulsory school age who, because of illness, would otherwise not receive suitable education.*" (DfE, 2013)

Once a CYP is referred to the HRET then the provision will be offered in the young person's home or appropriate community location (typically 5 hours per week). The HRET is a short-term provision, typically lasting up to a maximum of 12 weeks. The HRET will help guide schools in planning for the CYP's educational provision following the team's input, which may be a transition back to school, community venue or continued education at home with support provided by school.

4. Getting the school ready for the child or young person's return

CYPs with an ABI have a lot to contend with. The injury can impact on every aspect of their life – physical, social, emotional, cognitive, communication and self-care / independence. Therefore, the more preparation the adults do around their school return, the better the potential outcome.

This guidance is designed to support schools to think about the many factors involved in managing a CYP with an ABI. Some may apply, others may not. However, learning from previous cases has highlighted a number of first principles which schools should address, **ahead** of the young person returning to school. The diagram below highlights these:

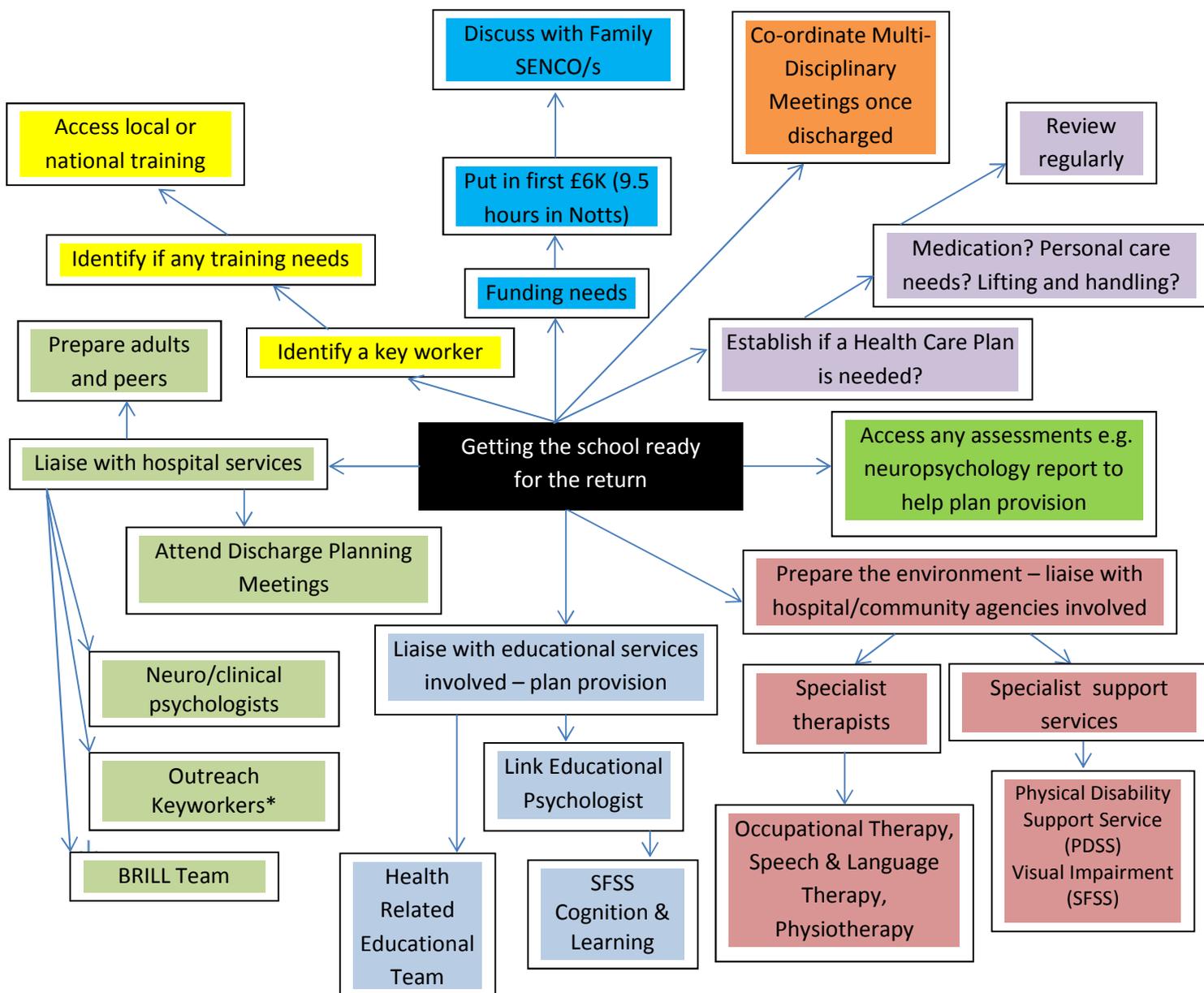


Figure 1: Getting ready for the CYP's return to school

*Louise Robinson (Paediatric Neuro-oncology Specialist Nurse Keyworker) and Alison Fletcher (Brain Injury Specialist, The Children's Trust in Partnership with Nottingham Children's Hospital) known from here on as Outreach Keyworkers.

4a. Preparing other adults

- Adults at school need to know key information about what has happened, and that a different response is required from them. However, it is crucial that the young person retains a sense of control over what is being shared with other adults
- Specialists from the hospital (e.g. Neuropsychologist / Outreach keyworkers) will usually offer to provide training and information about the CYP's condition
- Adults should carefully consider how information is to be exchanged between home and school
- Consideration should be given to how all staff, including lunchtime supervisors, cover/supply teachers will be briefed, and made aware of significant information which may require their action
- If adults have any further questions then they should know who they can contact, e.g. outreach keyworkers, from the hospital

4b. Preparing the child or young person's friends and other peers

There are a number of ways schools can support friends and peers of a CYP with an ABI in school:

- Firstly, it is important that schools check with the CYP and their parents/carers about the information they are happy to be shared before talking to their peers
- Peers should be given the opportunity to talk and share about the situation
- Specialists from the hospital will usually offer to meet with peers to share information and address any questions peers may raise
 - *For CYP with cancer, a CLIC Sargent Social Worker or Outreach Nurse from the hospital should be able to come into the school to explain what is happening and answer any questions peers may have*
 - For CYP with other forms of ABI, it may be possible for the Clinical Psychologist or Outreach Keyworker from the hospital to come into school to raise awareness and answer any questions. These professionals can usefully provide a point of contact if any subsequent questions are raised
- Inform other peers sensitively about developments and changes in the CYP in a calm and straightforward way. Talk to them in small groups and encourage them to ask questions and share their feelings. Pay particular attention to the friendship group of the young person as they can be a tremendous support system to their friend. However, they may need additional support to make sense of what has happened and what they can do to help
- Encourage peers/friends to maintain contact with their classmate through calls, texts, Face Time, Skype and social networking sites (if they are old enough). They could also send cards and visit where appropriate

4c. Health Care Plans

- Schools need to determine if a Health Care Plan (HCP) is required. The HCP identifies health/medical issues which may need to be addressed whilst the CYP is at school, e.g. administering medications, notifying of communicable (infectious) illnesses or emergency routines. An HCP outlines the action required to meet a child's immediate health needs and should not be confused with the Educational Health and Care Plan (the statutory process which previously resulted in a Statement of Special Educational Needs. EHCP are discussed in Section 6
- If there is a HCP, school staff must ensure that everyone who may need the information has access to it, including reception staff, midday supervisors and cover / supply teachers
- It is essential that there are clear routes of communication about any health needs between home and school – school staff must have access to direct numbers and emergency protocols. This is especially important for those young people whose treatment is ongoing
- *It would be rare for there to be an acute emergency, but if this occurs (as with any young person) call a 999 ambulance, and ensure that the crew are aware that young person is receiving, or has recently finished, cancer treatment and which hospital is/was treating them*

- Schools should consider whether there is any training staff need to attend, e.g. administering medication/undertaking personal care/lifting and carrying/ attending the 'Don't Judge a Book By Its Cover' course from the Child Brain Injury Trust
- *For CYP with cancer, staff may have concerns about the implication of the illness and treatment for the CYP in school. Specialist nurses are available to offer guidance and support, specific to the pupils needs. If a specialist nurse has not been in touch with school these can be contacted via the outreach keyworker*
- *All school staff need to understand the long-term effects of cancer treatments, such as fatigue, difficulty with memory or physical changes. The school community can do a great deal to support the situation This might include times when the CYP is not in school but continuing to learn in hospital or at home*

Sam's Journey: "The PE department grasped Sam's challenge to get him back on his feet and playing sport, they worked with him every day building up his muscle and strength and as a bonus also his confidence. We developed a link with the hospital Physiotherapist who made a work plan each month which was followed and adapted as he gained mobility."

4d. Entitlement

CYP are entitled to have 25 hours of educational provision per week. The use of part-time timetables should relate to the child's needs and should be part of a phased re-integration back into full-time schooling. This progression towards full-time education should be made under advisement of the MDA team working around the individual CYP.

4e. Funding

In Nottinghamshire support for CYP with additional needs is typically funded through monies allocated by the local authority to the 'Family' of schools (i.e. the secondary school and the associated feeder schools). This Additional Funding Needs (AFN) funding is allocated by the Family to meet the needs of the CYPs within that district. Schools 'bid' in for funding and the bids are moderated across the family of schools. Children and young people in Nottinghamshire do not require an Education Health Care Plan (previously known as a Statement) in order to access funding. Nottinghamshire differs from other local authorities in this respect.

For the most complex CYP, who has been identified as having needs exceeding those which can be funded through AFN, funding is provided through the Local Authority. If the CYP's needs are significant then an application for High Level Needs funding can be made to the Local Authority (moderated by the Family).

Nationally, each school must provide the first £6,000 of funding for an individual before they request additional funding. Therefore, in Nottinghamshire schools will be expected to make provision for the first 9.5 hours per week before they seek additional funding. A CYP with an ABI may eligible for consideration of additional funding if the ABI represents a significant change in their need. This should be discussed with the Family SENCo and other SENCos within the family of schools.

4f. Identifying a key person at school

- An appropriate key worker should be identified. This person should be able to work both at school and in the home as required. Careful consideration should be given to who is best placed to undertake the role (new staff may need to be recruited) and the keyworker should ideally be matched to the CYP. The adult needs to be empathetic but also resilient
- A key worker approach allows an adult to become familiar with the CYP's capabilities, strengths and areas of difficulty, so they can support with adaptations to the curriculum and tasks whilst also mediating the CYP's learning
- This approach is crucial as it allows one key adult to have a holistic overview of all the CYP's needs. This can be particularly helpful if issues arise and the keyworker needs to intervene on a CYP's behalf, e.g. if a CYP does not recognise there is an issue/lacks insight, or if they do not feel confident to broach an issue with other adults
- Appropriate training should be arranged for the keyworker, for example, courses focused on supporting the needs of a CYP after ABI organised by The Child Brain Injury Trust (Don't Judge a Book by Its Cover)
- Consideration should be given to the support and supervision systems around the adult in the key worker role
- School should ensure the provision is reviewed regularly and that respective roles within school are being appropriately maintained, e.g. class teachers / subject teachers are responsible for planning the provision

Sam's Journey: "The fact that that school embraced the problem of 'school and students with a brain injury' was really encouraging. To be able to offer the support of a person who has been on training courses with the ABI and also who was willing to adapt and implement learning methods is amazing. Other schools should use the service and be in a position to support their own students."

4g. Practical considerations

- Consideration should be given to how students with disabilities will negotiate the environment. For example, how will they access classrooms and different floors
- Particular attention should be given to how disabled pupils will evacuate the building in the event of an emergency
- Schools will also need to consider transitions between lessons and management of the start and end of the school day
- If the ABI results in personal care needs, e.g. support with toileting, then this is not a barrier to a CYP's return to education. Provision should be made as part of the school's reasonable adjustments. However facilities, resources and adaptations will need careful and timely consideration
- Safe manual handling training may be required, this is available from Physical Disabilities Specialist Service (PDSS)
- Occupational Health and PDSS can help a school assess the suitability of the learning environment and make any recommendations for adaptations

5. Working with the child or young person back in school

5a. Keeping the CYP actively involved

- It is crucial that adults working with the CYP consider their views, and involve them in decision making at an age-appropriate level whenever possible
- Adults should carefully consider how they access views of the CYP (e.g. involvement in meetings, planning, pen pictures etc)

Positive practice examples

- ✓ School staff could plan to use tools such as a CYP-led pen picture as a vehicle to communicate about issues important to the CYP. Sam co-wrote his pen picture with the Educational Psychologist and this can be found in Appendix 1. Pen pictures should be reviewed regularly with the young person to reflect any changes in needs
- ✓ Some CYP may want to share more about their experience. For example, Sam made a power point about his experiences in hospital which he shared with his peers at school in an assembly
- ✓ *Young people with cancer attending cancer centers in the UK will be part of a programme called 'Beads of Courage'. The young person on treatment collects beads for different parts of their treatment e.g. each time they have a blood test, chemotherapy treatment or a scan. The young person could bring their chain of beads to school to share with peers what treatment is like for them. This is a visual way for classmates to grasp what their friend is going through*

Sam's Journey: "One of the most powerful things to help change the mind set of those in school was Sam's film. He ended up presenting almost all of this to his peer group with some support from Kelly (Teenage Cancer Trust). The fact that he had driven its production and content made it an amazing project for him. This gave his peers the opportunity to chat about his condition / journey and also to talk about their feelings, fears and how they felt school should have handled the information about Sam and his condition." (See resources section for links)

5b. Organisational issues: thinking flexibly

- The school will need to adopt a flexible approach when the CYP returns to school, certainly in the first instance, and in many cases, in the longer term. There will be a need for flexibility within a day and even within **each** lesson within that day!
- Consideration should be given to timetables, time and nature of support in school, access to social activities and time with peers, homework requirements and behaviour support.
- These elements should be regularly reviewed and revised as required
- School staff are likely to need to adjust their expectations of academic performance because of the CYP's gaps in knowledge, reduced energy, confidence or changes in ability depending the site and mechanism of the acquired injury
- Assessment of retained skills is crucial, as is the ongoing monitoring of a CYP's rate of progress. This should inform the provision as the reintegration to school progresses and be done informally and sensitively to avoid making the child or young person anxious

- Wherever possible the CYP should be enabled to stay in the same ability sets as before, unless they specifically want to change groups

Positive practice examples

- ✓ A flexible timetable should be arranged, perhaps starting with subjects the CYP likes, staff they feel most comfortable with or areas of the curriculum in which they are likely to achieve
- ✓ School staff should consider how the CYP will record and demonstrate their ideas/understanding. They should be given the opportunity to explore a range of methods, e.g. record their ideas orally into a voice recorder, use an adult to scribe, use a picture / chart mind map
- ✓ Due to the frequent difficulties with speed of processing, fatigue and attention experienced after ABI, staff should ask themselves whether the CYP really needs to write information down, or whether it could be provided in an alternative format. CYP with an ABI are likely to struggle with copying from the board, so should not be asked to do this
- ✓ It is crucial to have one key adult that the CYP can go to if they are upset or finding school difficult. It is also useful to have a 'Plan B' person for times the usual person is not available
- ✓ In secondary schools, CYP can be given a card which enables them to leave class if they are feeling overwhelmed/fatigued etc, without having to explain too much
- ✓ Many CYP with an ABI find it extremely useful to have an allocated place in school where they can rest and recuperate if they are particularly fatigued
- ✓ Managing the demands of homework at home can be overwhelming for many youngsters with an ABI. Therefore, where possible it can be helpful to let the CYP do it at school with appropriate access to support

Sam's Journey: "To have the Educational Psychologist, Clinical Psychologist and Teaching Assistant all working together gave Sam great confidence. His anxiety/panic attacks subsided (amazingly he had taught his TA how to manage them!) and he was able to remain at school. That confidence led to greater enthusiasm for his subjects, which in turn led to success."

5c. Planning support: Every day is different!

- It is important to consider both the academic and social aspects of school. Therefore, the CYP may be on a reduced timetable, but schools should think about opportunities to include social time when planning provision e.g. morning session plus lunch time
- Schools need to think flexibly about provision. It may be appropriate to timetable rest periods into the day or to have space where some learning can be conducted in quieter, calmer environments.
- Secondary schools should think about the number of subjects the young person is being asked to undertake, and consider whether there is a need for them to focus on fewer key subjects
- Teaching staff should all be made aware of issues raised in the neuropsychological assessment, HCP and any additional assessments completed. Planning of lessons should incorporate any additional support or resources required by the CYP to facilitate their learning
- Schools will need to plan for the absence of regular teachers and teaching assistants. This should involve thinking about how and when the CYP will be informed, the provision of information to cover staff, and further support plans should issues arise

- Arrangements should be made for the CYP to move around the school easily, e.g. allow them to leave lessons five minutes early to avoid the rush. Thought should be given issues such as how they will manage their belongings, break/lunchtime support/provision, and whether they need access to any lifts/disabled facilities etc
- Schools should think about the provision on a day-by-day basis and review regularly. CYP are entitled to 25 hours provision per week, but this may need to be achieved over a phased return. This can be agreed between school and parent/carers in agreement with educational support services.

Positive practice examples

- ✓ Trial to identify successful support strategies, e.g. visual timetables, flashcards – trial and error may be needed to identify what helps. The provision of handouts, lesson maps, keyword lists and other resources, can allow a CYP with an ABI to better access the content of the lesson, and keep up more effectively
- ✓ Assess if there are any self-help needs e.g. changing for PE – don't presume previous skills have been retained, so check it out rather than make assumptions about skill levels
- ✓ Some CYP may not want to be left out during PE despite tiredness or other physical limitations. Their family will be aware if there are specific restrictions on them doing PE due to medical devices or vulnerabilities which need consideration. Include the CYP as far as possible, e.g. allow them to take part for 20 minutes rather than the full session, or find other ways for them to participate e.g. as referee or scorer. Any queries can be directed to the Outreach Keyworkers
- ✓ Processing information at speed is a significant issue for many young people with an ABI – ensure all staff are aware of the implications for the CYP and give consideration to the teaching style used
- ✓ Expect the unexpected! For example, post ABI Sam could read a digital clock but not an analogue clock face and yet all the clocks at school were analogue
- ✓ Try not to assume anything – check it out with the CYP themselves

Sam's Journey: "As Sam gained confidence so did the school and as the months went by they were able to offer more and more. Some ideas not so good, but others were fantastic. Sports he could no longer play he coached! Lessons that needed too much re-learning were taken out of his timetable, not easy learning French and German when you are re-learning English!"

5d. Specific considerations when supporting a CYP with cancer

- *Radiotherapy and chemotherapy can have significant consequences both during, and after their use (even years/decades later). CYP being treated for cancer may present with additional cognitive issues*
- *The School Attendance/Welfare Officer should be informed if the CYP is absent for a prolonged period of time for medical reasons. If they are being taught in hospital or at home, they should remain on the school roll. Instead of being marked 'absent' they should be marked as 'educated offsite', or 'dual registered' if they are in a hospital school*
- *Class/subject teachers need to provide appropriate work for the CYP to fit around treatment and how they are feeling. Teachers can use email and/or provide online learning so that school work can be flexible depending on where the learning is happening*

- *It is important that staff are informed sensitively and in a timely manner about developments and changes, e.g. a meeting so that everyone hears important news at the same time. This also ensures that staff knows where to get support if they need it*
- *All staff should be made aware of any agreed adaptations, and revised arrangements should be circulated to all staff, e.g. a CYP may want to wear a baseball cap, not take part in PE, leave a lesson early, come in part-time or have homework extensions. All staff are responsible for making such reasonable adjustments*
- *The CYP with cancer-related ABI should be reviewed regularly via the termly Springboard meeting in both the short and long-term, as the impact of treatment can have consequences for decades to come*

Positive practice examples

- ✓ *Consideration should be given to the issue of absence – the CYP person may well need to attend medical appointments or have time off following treatment. Schools should think about how this may relate to systems, e.g. prizes for 100% attendance. It is important to ensure the CYP's authorised absence does not penalise others, e.g. class-based rewards, and to consider the implications for child's relationships with peers and the impact of such issues on their self-esteem*
- ✓ *Professionals from the hospital (e.g. BRILL team, key workers, neuropsychologists) are available to provide updated information and training to staff teams. It can be beneficial to plan this into INSET/training days, or staff meetings to ensure all staff have access to the necessary and up-to-date information about a CYP's medical situation and current support requirements*

5e. Exams

Sam's Journey:” The exams officer found there were many ways in which Sam could be helped during the GCSE, not just extra time. It was worth spending time going through the neuropsychology report etc and getting every available bit of support in place.”

The SENCo should liaise with the school's Exams Officer regarding access arrangements and special consideration. The examinations officer should be fully aware of the issues so as to be able to apply to the exam board for the necessary considerations. These applications are looked at on an individual basis and the adjustments possible will depend on specific subject requirements and medical evidence.

If the CYP is due to sit external exams, the examinations officer should prepare to make access arrangements in case they are necessary. These might include:

- Up to 25% extra time
- Reader or scribe
- Use of a laptop
- Taking the exam in hospital, at home or in a separate room at school
- Rest breaks
- When they sit the exams e.g. schedule for the morning

It may also be appropriate for the CYP to receive 'Special consideration'. This is an adjustment to a grade to reflect an illness or 'indisposition' at the time of the exam. This would be appropriate if, for example, a CYP was having chemotherapy at the time of the examination. These arrangements apply to Key Stage 2 SATs, Key Stage 3/4 ongoing timed assessments and GCSEs.

Sam's Journey: "GCSEs were approached one at a time, being completed in 6 month bursts to coincide with national exam dates. Each achievement led to another subject being tackled and soon Sam had gained an impressive range of qualifications despite time off for treatment and hospital appointments."

5f. Transition points in education

- Transitions both within and between schools should be subject to careful planning and liaison with both the CYP and their family, and wider agencies as appropriate. There is likely to be a need for an enhanced transition. Changes in the CYP's physical environment should also be considered
- If a CYP is moving to a new class or school, the new teachers, school and support staff should be informed and provided with as much information as possible. Any new setting should be made aware of the ABI. This remains important, even if the ABI is not recent, as some CYP may experience long-term effects which can impact on their learning long after the initial injury
- Arrangements should be made for the CYP to meet new teachers/staff well in advance, in order to discuss their needs and reduce anxiety about the transition
- New settings should be encouraged to notice and follow-up signs of distress, poor performance or anxiety. Even after discharge, schools can re-refer CYP to the Outreach team / neuropsychologists for further support / advice if new issues emerge as a result of a transition, e.g. moving from primary to secondary means managing many new subject teachers and moving around a large school site

5g. Aspirations and Post-16

Sam's journey: "Sam wanted to be a physiotherapist. Therefore, a bespoke package was devised for his Sixth Form which involved being part of the PE department teaching at school, coaching in the community and working towards his Maths GCSE in Year 12. The intention was that he then address English GCSE in Year 13 thereby giving him the greatest time to reacquire his literacy skills which were most affected by his ABI." Dr Nicki Hammill (EP)

- It is important to make really meaningful links between school, agencies and the community in order to facilitate the CYP's aspirations
- CYP with ABI are likely to need an enhanced transition to post 16 provision
- Personalised provision may well be required beyond statutory school age (see EHC Plans below)

6. Education Health and Care Plans (ages 0-25)

In September 2014, the previous 323 Assessment which led to a Statement of Special Educational Needs was replaced by an assessment of a C&YP's Education, Health and Care needs. The result of an agreed assessment is an Education Health Care Plan. This plan aims to bring together the different support services operating around CYP with the most complex needs to create a plan about their provision.

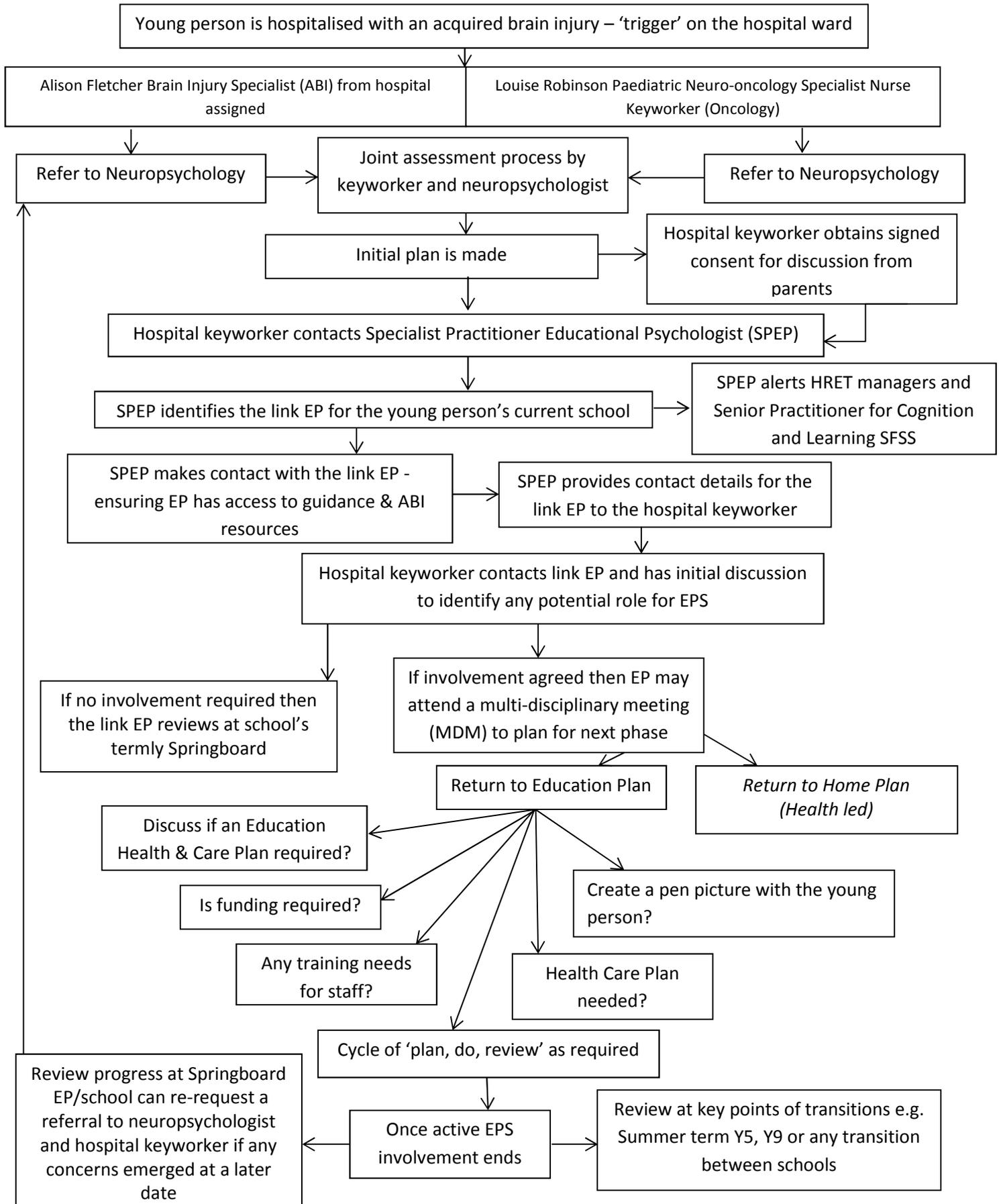
Professionals, parents or schools can request an EHC needs assessment. In Nottinghamshire, initial information goes to a panel of commissioners from the different areas of health, education, social care and post 16 who make the decision about whether the request should be agreed. If an assessment is agreed then each of the agencies will make a professional contribution around the needs of the C&YP. In addition, parents and the young person have their own role to play in contributing information. If an EHC plan is subsequently agreed from the assessment, the views are then brought together into an initial draft, which sets out the needs of the CYP, identifies outcomes and describes the provision required. A multi-agency meeting is the forum to discuss the proposed plan and negotiate amendments. The final plan is then issued and reviewed annually. The plan can now extend until the age of 25 if the young person remains in education. For further information please refer to the Code of Practice (DfE, 2014).

7. Interagency Collaboration – the Sam White Pathway

This document builds on prior experiences of CYP who have made a successful return to education after an ABI. It aims to support schools, CYP, agencies and parents to meet the needs of a CYP returning to school after an acquired brain injury. The document promotes the need for proactive, collaborative planning by schools, agencies and families, in order to enhance the educational future for this unique cohort of children and young people.

The Educational Psychology Service have identified that the Specialist Practitioner Educational Psychologist for Emotional Health and Well-being (SPEP) will be the named point of contact for Neuropsychology Services based at the QMC. In order to facilitate good practice around managing CYP with ABIs we have devised a pathway which identifies how health and education will aim to collaborate once a CYP in Nottinghamshire has been identified as having had an ABI (see overleaf):

The Sam White Pathway - Interagency Collaboration



This pathway should be followed for each CYP where a new ABI has occurred. If school staff or agencies are aware of a CYP living in Nottinghamshire or attending a Nottinghamshire school with an existing ABI then they should be raised at the termly Springboard meeting as part of the monitoring of this potentially vulnerable group.

Summary

“The purpose of this document is to use to the best advantage all that has been learnt during the years spent returning Sam to education and educating those who worked with him. Sam was focused and determined following his brain injury, he was going to succeed despite his illness and he wanted to show that with the appropriate help and more importantly understanding he would get there in his own way and own time. We all met with frustration, but eventually became a great team and were rewarded with success, confidence and a brilliant smile! The knowledge gained and new pathways developed proved to be so powerful that the decision was made that we should move this forward and use that knowledge to provide a better pathway for others with a brain injury returning to education. This will be Sam’s Legacy.”

Pam White

Co-created by Mrs Pam White (parent), Dr Emily Bennett (Clinical Psychologist in Paediatric Neuropsychology, Nottingham University Hospitals NHS Trust) and Dr Nicki Hammill (Specialist Practitioner, Educational Psychologist, Nottinghamshire County Council).

With grateful thanks to Louise Robinson (Paediatric Neuro-oncology Specialist Nurse Keyworker) and Alison Fletcher (Brain Injury Specialist, The Children’s Trust in Partnership with Nottingham Children’s Hospital) for their support in the editing of this document.

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References

These resources are available to download:

- Department of Education (2014) *Special Educational Needs and Disability Code of Practice: 0 to 25 years*
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/341058/Code_of_Practice_approved_by_Parliament_290714.pdf
- Department of Health (2004) *National Service Framework for Young People and Maternity Services Acquired brain injury*
<http://dera.ioe.ac.uk/id/eprint/6236>
- Peterson Broyd, B; DeJong, M; Peacock, S. and Hargrave, D. (2006) *Returning to school: A teacher's guide for CYPs with brain tumours* The Royal Marsden Hospital Foundation Trust
<http://www.royalmarsden.nhs.uk/diagnosis-treatment/children/pages/teachers-guides.aspx>
- Peterson Broyd, B; Pritchard-Jones, K. and Edwards, L. (2008) *CYPs with cancer: A guide for teachers*. The Royal Marsden NHS Foundation Trust
www.royalmarsden.nhs.uk/teachersguide or www.schoolsnetwork.org.uk/academies

Signposting to organisations and resources

- Walker, S. and Wickes, B. (2005) *Education of Children with Acquired Brain Injury*. David Fulton: London.
- The Children's Trust has a very wide range of resources for families, young people and professionals in relation to ABI

<http://www.thechildrenstrust.org.uk>
<http://www.braininjuryhub.co.uk>
- Child Brain Injury Trust
www.childbraininjurytrust.org.uk
- *The Brain Tumour Charity*
www.thebraintumourcharity.org
- *JT Timmy Teens TV – videos and resources made by young people with cancer*
http://www. Sam's own films can be accessed via <http://jtvancersupport/films-by/sam-white>
- *Sam's presentation to school peers and teaching colleagues about his experiences can be accessed via <http://www.youtube.com/channel/WUzpbEmUh34mA>*

Appendices

- Appendix 1: Checklist for preparing for the return to school
- Appendix 2: Sam's Pen Picture – blank proformas are available on the EPS School's Portal page.

Appendix 1: Checklist for preparing for the child or young person's return to school

Action required by school	Who? When?	Date achieved
Attend multi-disciplinary meetings at the hospital		
Attend MDM discharge planning meeting at the hospital		
Liaise with health professionals involved		
Liaise with parent / carers		
Liaise with educational support services involved		
Liaise with support services around the environment		
Refer to any new agencies required to be involved e.g. PDSS		
Access the neuropsychology report when planning provision		
Identify a key worker and any initial training needs		
Allocate block funding (£6K) and discuss any additional needs with Family		
Co-ordinate multi-disciplinary meetings once discharged from hospital		
Establish if there is the need for a Health Care Plan e.g. administering medication or toileting needs. Any training implications for staff?		
Ascertain the child or young person's views about what information can be shared		
Prepare staff and peers with support from the Outreach team, BRILL and / or psychology services		
(i) Review regularly within school (as determined by need)		
(ii) Review regularly via Springboard meetings (termly)		
Are exam considerations necessary e.g. Key Stage 4?		

Appendix 2: An example of a pupil led pen picture

Background: In March 2009, Sam (Y7) had an undiagnosed brain tumour which bled, causing stroke like symptoms. The tumour's development and the subsequent bleeding left Sam with a traumatic brain injury. Initially, Sam could breathe, swallow and hear but he had lost all other functions. Sam has had to relearn every single skill e.g. how to walk, get dressed. All prior knowledge/learning was also lost. Sam had chemotherapy and radiotherapy which can cause further deterioration cognitively for several decades to come

Before the tumour Sam was an above average student academically (Level 5 at the end of Year 6). Sam returned to school in Year 9. He is now in year 10 and will be doing a reduced GCSE curriculum. Sam has a brilliant 'can do' attitude to life and school. He is an ambassador for organisations working in the field and has recently spoken at the European Parliament and he contributes to Jimmy Teen's TV. He coaches Boccia and is learning to play golf. He is determined to do well at school, but doesn't always let staff know how he is actually, which changes on a day-to-day basis

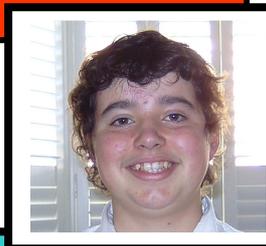
The brain injury has implications for how he needs to learn and the other factors, such as anxiety, pain and temperature regulation, mean that **all** adults working with Sam need to have a clear understanding of his needs so as to make the appropriate adjustments

For further information visit:

www.headstartcancersupport.org.uk

www.braintumourtrust.co.uk

www.cbtrc.org



Things that staff need to know

- Sam has an acquired brain injury which should be considered significant, despite how he presents to others
- Sam has difficulties processing information and with his verbal memory. This has huge implications for teaching when information is delivered orally
- Sam can experience anxiety and this feels like the symptoms of the tumour so it is really frightening;
- Sam suffers ongoing hypersensitivity to pain which impacts on his well-being and learning
- Sam is easily fatigued especially after strenuous activities – his recovery time is days not hours
- Sam experiences neuropathy which affects his co-ordination and can make him hypersensitive to touch
- Sam is not allowed to do contact sports where he may bang his head – he has a health care plan
- Sam's temperature regulation is impaired so he cannot identify if he is too hot or too cold. Adults need to monitor and intervene as necessary e.g. suggest Sam removes his jumper
- Sam is keen to achieve but can be reluctant to tell staff if he doesn't understand or can't keep up
- Sam's needs change on a day by day basis

How staff need to support Sam's learning

- All verbal instructions should be short and concise, with frequent prompts, to reduce pressure on Sam's verbal memory
- The speed at which Sam processes information is significantly slower than his peers. Sam will need additional time to process, and record, information
- 'Over-learning' helps Sam to retain information e.g. using a digital voice recorder to record the teaching input would allow him to listen to the teaching input and instructions again
- Any task needs to be broken down into small, manageable chunks with clear, concise instructions
- Use a question to assess if Sam has understood what is being asked of him, rather than simply asking "Do you understand?"
- It is not appropriate to expect Sam to 'copy' information from either a whiteboard or worksheet. Try using a digital camera to record diagrams, tables etc
- Consider use of a scribe for tasks which require any extended written response from Sam
- Wherever possible, ask Sam to record verbal information in a visual format e.g. using a spider gram. This will help Sam structure his response and reduce his need to always record work in long hand
- Ask yourself "How can Sam demonstrate his learning?" Does he need to always write things down in full sentences?
- Support Sam with managing his learning, especially tasks which demand him to work independently e.g. homework, and/or course work. Sam will take much longer to do the work so differentiate your expectations for Sam or give extra time
- Be mindful of giving tasks which invoke significant stress/anxiety e.g. timed assessments. Staff should ask themselves, "Why am I asking Sam to do this task?" If it is unavoidable then plan for Sam needing support such as a scribe and extra time
- Sam is articulate and his verbal skills are one of his strongest assets so he should have opportunity to work collaboratively with a range of peers to continue to develop these skills
- Sam's memory of vocabulary was wiped clean by the brain injury. Therefore, he is now relearning words he previously knew, as well as acquiring new vocabulary. Give Sam any new words for each new topic with the associated explanation