

Educational charter: for young people with a brain tumour

This charter is based on relevant laws and statutory guidance in **Wales**, which protect the rights of young people with health needs or disability to:

- a good quality education
- access to the same opportunities at school/college as any other young person
- the provision of the individual support they need to achieve this

This charter will guide you on the support that young people have a right to receive and the timescales in which they should receive it. It can also be used by schools/colleges to help receive extra funding for support for the young person.

- Young people have a right to full-time education (or as much as their condition allows) despite disability or other health needs, regardless of where they are educated including school trips and physical education.
- This right includes the provision of support to meet the young person's individual needs, including social and emotional needs.
- Local authorities and schools/colleges should have a written, publicly accessible policy statement about their arrangements to comply with their legal duty to young people with additional health needs/disability.
(This should apply to all young people regardless of their health condition and regardless of how much time the young person is able to attend school/college. It should be regularly reviewed).
- Local authorities should have a named officer responsible for the education of young people with additional health needs.
- Schools/colleges should have a named person responsible for implementation of the school/college policy. Parents should be told who these people are.
- The local authority or governing body must ensure that arrangements are in place to support pupils with medical conditions and that processes/policies are fully implemented.
- All schools have a duty to provide reasonable adjustments for disabled pupils, including providing auxiliary aids and services.

- Local authorities schools/colleges should hold, chair and document a planning meeting with medical professionals and the young person's family to consider medical evidence and set up an individual development plan.
(This is not the same as an education, health and care plan (EHCP), which may not be required. The individual development plan should be reviewed at least annually, or earlier if the young person's needs have changed).
- Young people with complex health needs should have an identified key worker to ensure delivery of the care plan.
- Young people should be involved in decisions from the start, in ways reflecting their age and maturity.
- Local authorities should have at least one educational psychologist to work with home/hospital tuition services and other support services.
- Local health boards normally designate a paediatrician, with specific responsibility for children and young people with additional learning needs (ALN) - the new name for special educational needs (SEN).
- It is absolutely essential that there is clear communication between the different agencies, services, professionals and the parent/carer and pupil concerned.
- Education and support should be supplied as soon as it is clear the young person will be away from school for 15 days or more, either in one absence or over the course of a school year.
- Arrangements for education/support during an absence from school, should be put in place by the sixth day of absence or, if the absence is planned, by the first day of absence, or as soon as they are able to benefit from it.

- Young people educated at home due to a medical condition should receive a minimum entitlement of five hours teaching per week.
(This should be increased where necessary to enable them to keep up with their studies, particularly when approaching public examinations).
- Schools should ensure that young people can stay in touch with the school and their peers while they are away.
- The school should monitor work missed and plan, in liaison with the hospital/home tuition service, where involved, to help a young person "keep up rather than having to catch up".
- School policies and practices need to be positive and proactive to welcome the young person back into school and to assist successful reintegration. Consultation with the young person and parents about concerns, medical issues, timing and pace of return is important.
- Staff working with the young person should have suitable training and information about the young person's health condition and its effects.
(This includes cover arrangements for staff absences and supply teachers).
- The school/college's policy should be clear about the procedures for managing medicines, including written records of all medicines administered.
- The school/college's policy should be clear about what to do in an emergency.
- Applications for suitable arrangements should be made to awarding bodies of public exams as early as possible.

Young person Any young person in nursery, school or college up to the age of 18 years.

Disability A physical or mental impairment which has substantial and long-term adverse effect on that person's ability to carry out normal day to day activities. Some specified medical conditions, including cancer (high grade tumours), are considered as disabilities, regardless of their effect.

Substantial adverse effect A limitation that is more than the normal differences in ability that might exist among people. It makes it more difficult and time consuming for the person to carry out an activity.

Long-term Lasting, or likely to last, for at least 12 months.

Local authority or governing body Or the proprietor in independent, non-maintained special or foundation schools.

For details about the legislation, see thebraintumourcharity.org/legal-framework-wales

A draft Bill is due – the Additional Learning Needs and Education Tribunal (Wales) Bill – that will make provision for a new statutory framework for supporting children and young people with additional learning needs (ALN). This will replace existing legislation surrounding special educational needs (SEN) and the assessment of children and young people with learning difficulties and/or disabilities (LDD) in post-16 education and training. Many of the above rights will remain.

