5-ALA

What is 5-ALA?

5-Amino-Levulinic Acid (5-ALA), or Gliolan, is taken orally by patients with high grade tumours several hours ahead of surgery (5-ALA may also be referred to as the pink drink). During surgery the surgical team use ultraviolet light to identify cancerous tumour cells which glow pink as a result of 5-ALA. This enables the surgeon to resect more cancerous tissue and less healthy tissue which can have a positive effect on the symptoms and side effects that a person experiences after treatment.

Because 5-ALA is taken orally it is classified as a treatment and not a medical device. The research is currently around use for high grade gliomas. There is no evidence that 5-ALA improves resection of low grade tumours.

The Brain Tumour Charity’s View

Survival for a high grade brain tumour is poor and there are limited treatment options. 60% of people diagnosed with a high grade brain tumour will die within one year and just 19% of people will survive for five years or more (1).

The treatment outcome for high grade tumours is typically dependent on prognostic factors such as characteristics of the patient and the location and size of the tumour. Research has shown that the extent of surgical resection of tumour tissue can influence responsiveness to treatment and that 5-ALA can improve resection of the tumour and improves progression free survival for high grade tumours when compared against standard practice in which it is not used (2–4).

Research shows that 5-ALA is cost effective when compared against current practice (5,6). The approximate cost of a 1.5g phial of Gliolan is € 980 (wholesale – 2009) (5). There are other factors to consider. The EMA state that surgeons must attend a training course to support safe and effective use and the majority of centres have surgeons trained in its use. Surgeons must have access to a fluorescence microscope, which are prevalent in the majority of centres. MRI scans pre and post-surgery should be standard practice, however this is not always the case and some centres have a resource deficit. Where access to MRI is more limited the use of 5-ALA may also be limited.

Additional costs can be offset by future savings including a reduction in second-line chemotherapy, a reduction in re-operation rates and a reduction of dexamethasone usage in the long term.

The European Medicines Agency (EMA) have authorized 5-ALA for use in high gliomas (3). 5-ALA is not commissioned nationally through either NHS England specialised commissioning or a National Institute for Health and Care Excellence (NICE) technology appraisal. There is currently no NICE clinical guidance for its use (NICE clinical guidance recommends standards of treatment and care that an individual with the specified condition should receive but implementation is not legally binding) (7).
The use of 5-ALA is not standard clinical practice and access for people affected by a brain tumour varies. The Brain Tumour Charity believe that people affected by a brain tumour should have equal access to treatment and care.

We would strongly urge that 5-ALA be included in the NICE guidance Brain tumours (primary) and brain metastases in adults which is currently in development and due to be published in June 2018 (5). This guidance will provide recommendations for the management and care of brain tumours in the NHS at a national level. Following this we believe that NICE should carry out a technology appraisal and that the treatment should be commissioned nationally to enable everyone with a brain tumour access where clinically relevant.

In the interim we recommend that neurosurgical centres across the UK commission 5-ALA locally. At present surgeons must make a business case to introduce a new interventional procedure and outline evidence of clinical efficacy and cost effectiveness. The decision to commission will be based on a number of factors which include resource allocation and perceived priorities.

**Where is 5-ALA currently available?**

Not all Trusts fund access to 5-ALA. An individual who does not have access to 5-ALA may be able to access it through an individual funding request, private care or a clinical trial. The individual’s clinical team will be best placed to give advice on the course of treatment and discuss with the individual what options are available.

We are funding a piece of research that uses 5-ALA to look at the residual tumour cells left post surgery (8).

**What we are doing**

We will be working with NICE and NHS England to ensure equal access. We will follow closely and advise where appropriate the development of the Brain tumours (primary) and brain metastases in adults guideline and urge the inclusion of 5-ALA.

We have published a press release around unequal access to 5-ALA and have included it in our Patient Pathway Guide which highlights the best standard of care and treatment a person affected by a brain tumour in the UK should receive.

We will be actively campaigning to make 5-ALA available across the UK to ensure that every person affected by a brain tumour has access.

**References**


