Cryotherapy (freezing treatment) to reduce the risk of retinal detachment in Stickler syndrome

Stickler syndrome ([www.stickler.org.uk](http://www.stickler.org.uk)) is a group of genetic (inherited) disorders associated with short-sight (myopia), retinal detachment, cleft palate, deafness and arthritis. There are at least five different types of Stickler syndrome, but the majority of sufferers have either type 1 or type 2 Stickler syndrome. In Stickler Syndrome the risk of visual loss or blindness through retinal detachment is very high.

Retinal detachment is a condition where the light sensitive 'film' at the back of the eye becomes separated as a result of a retinal tear or tears. For further information about retinal detachment, visit the Vitreo Retinal Service website: [www.vitreoretinalservice.org](http://www.vitreoretinalservice.org) or ask your consultant or specialist nurse for further information.

Patients with Stickler syndrome are at particularly high risk of an unusual form of retinal detachment due to giant retinal tear (GRT). This is a particularly serious and complex situation where the retina tears part or all the way around its circumference (figure 1). In addition, because of the inherited nature of the problem, both eyes of an affected patient are at equally high risk. Studies in both the UK and the USA have shown that without preventative treatment the majority of patients with Stickler syndrome will suffer a retinal detachment in one or both eyes.

Figure 1 Giant Retinal Tears
Prevention of retinal detachment is especially important in children as they are often unaware of changes in their vision. They also quickly compensate for sight loss and therefore often present late, by which time it may be more difficult or impossible to salvage useful vision.

In contrast to some other forms of retinal detachment, the tendency for giant retinal tear in Stickler syndrome means that it is possible to carry out preventative treatment to reduce the likelihood of detachment or blindness in affected patients.

Cryotherapy (freezing treatment) is performed under a general anaesthetic and takes about 40 minutes, after which you will normally stay in hospital overnight. There will be a review by your surgeon the following morning, before you go. As with any medical therapy, no treatment has a one hundred percent success rate, but the surgery is aimed at substantially reducing the risk of retinal detachment. Our current research suggests that it reduces the risk by approximately ten-fold in patients followed up for an average of 15 years.

For the first 48 hours after surgery it is normal for the eyes to be mildly uncomfortable, puffy, red and watery. This may be more pronounced on the second day than the first. However, these symptoms gradually subside over a week to ten days.

In general, children tend to ‘bounce back’ and recover more rapidly than adults, but you should still expect them to feel rather miserable for about 24 hours. The eyes will remain swollen for about 48 hours and red for about a week with near vision returning to normal within three to four weeks.

Regular Paracetamol (if required) for the first few days should help with any pain.

The cryotherapy ‘glue’ normally takes several weeks to mature to full strength and the surgeon will therefore review progress after approximately four to six weeks. If you or your child have any concerns about the vision of either eye at any time, you should get in touch with our Vitreoretinal Service (contact details below). The service is available for any concerns following surgery – or at any time there is concern about vision.
Are there any risks with cryotherapy

The surface of the eye and the eyelids will be swollen and puffy for a week or so. This can be particularly troublesome in adults who are nearing the age for needing reading glasses and can last for six to eight weeks.

What are the alternatives to having cryotherapy for prevention of retinal detachment?

Some people may choose not to have cryotherapy. In all patients it is very important to look out for symptoms of retinal detachment/retinal tears (new floaters, spots in the vision and shadow advancing from the edge of the field of vision) and seek prompt specialist treatment.

The Addenbrooke’s hostel

Addenbrooke’s are now pleased to offer Ophthalmology patients who live outside of the catchment area free overnight accommodation in a hostel which is on the hospital site. This will allow patients who have a lengthy journey to come to Cambridge to stay the night before surgery or the night after surgery.

Glossary

Vitreous: Jelly-like substance filling the back of the eye
Retina: Light sensitive layer of the eye
RD: Retinal Detachment
GRT: Giant Retinal Tear
PVD: Posterior Vitreous Detachment
Prophylaxis: Preventative treatment
Cryotherapy: Localised freezing therapy
Useful contacts

Vitreoretinal Service
Box 41
Addenbrooke’s Hospital
Cambridge University Hospitals NHS Foundation Trust
Hills Road
Cambridge
CB2 0QQ

Website: [www.vitreoretinalservice.org](http://www.vitreoretinalservice.org)
Telephone: 01223 216701
Fax: 01223 217968
Emergency Telephone: 01223 217778 (Monday to Friday 9am until 5pm)
Emergency Telephone: 01223 216916 (Evenings and weekends)

Annie McNinch, Stickler Specialist Nurse: 01223 348843 for general enquires.

Stickler Syndrome Support Group
P.O. Box 371
Walton on Thames
KT12 2YS
Telephone: 01932 267635
Website: [www.stickler.org.uk](http://www.stickler.org.uk)
E-mail: info@stickler.org.uk
Addenbrooke’s is smoke-free. You cannot smoke on site. For advice on quitting, contact your GP or the NHS smoking helpline free, 0800 169 0 169

Please ask if you require this information in other languages, large print or audio format: 01223 216032 or patient.information@addenbrookes.nhs.uk

Informacje te można otrzymać w innych językach, w wersji dużym drukiem lub audio. Zamówienia prosimy składać pod numerem: 01223 216032 lub wysyłając e-mail: patient.information@addenbrookes.nhs.uk

Polish

Se precisar desta informação num outro idioma, em impressão de letras grandes ou formato áudio por favor telefone para o 01223 216032 ou envie uma mensagem para: patient.information@addenbrookes.nhs.uk

Portuguese

Если вам требуется эта информация на другом языке, крупным шрифтом или в аудиоформате, пожалуйста, обращайтесь по телефону 01223 216032 или на вебсайт patient.information@addenbrookes.nhs.uk

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Cantonese

Bu bilgiyi diger dillerde veya büyük baskılı ya da sesli formatta isterseniz lütfen su numaradan kontak kurun: 01223 216032 veya asadaki adrese e-posta gönderin: patient.information@addenbrookes.nhs.uk

Turkish

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Bengali