Frequently Asked Questions

Below are some of the questions we are asked most frequently about Sydenham’s Chorea.

How do you test for Sydenham’s Chorea?

There is no definitive test for Sydenham’s Chorea. The diagnosis is made by a doctor who needs to listen to the history of symptoms, observer the child and make a physical examination. Often, investigations are carried out to rule out any other condition that may explain the symptoms, and this can include blood samples. Blood tests and throat swabs looking for signs of infection with the Streptococcus bacteria that can trigger Sydenham’s Chorea can be helpful, but the diagnosis does not depend on these tests.

When the diagnosis of Sydenham’s Chorea is suspected, a child will be referred to a Paediatrician (a children’s specialist). The Paediatrician may look for help from a further specialist called a Neurologist. They will ask about the history of the symptoms, examine the child, organise any investigations required (which may sometimes include an MRI brain scan), and may ask other doctors to see the child before making a diagnosis, if appropriate.

Can childhood St Vitus dance / Sydenham’s Chorea cause heart disease in adulthood?

Children with Sydenham’s Chorea (often known as St Vitus dance or Chorea Minor) can have problems with their heart. Sydenham’s Chorea is a form of Rheumatic Fever, which can cause inflammation of the heart and lead to abnormalities with the heart valves. To protect against this, children are prescribed an anti-biotic. We know that some children can go on to experience heart disease in adulthood, however every case is different. Sometimes the heart valves are affected by Rheumatic Fever in a way that has only very minor impact on a child’s life as long as they continue to take antibiotics throughout their childhood.

How long does Sydenham’s Chorea last?

The movement disorder (chorea) almost always settles down either on its own, or with the help of medication. This can be quite rapid, but it can take months or longer, and varies from patient to patient. Occasionally a very mild form of chorea will persist. Symptoms can vary over time and the movement disorder is often more noticeable if the child is tired or unwell. We know that the movement disorder can come back later in childhood, however it is usually less severe and this will settle down over time. Some children go on to develop tics, which are a sign of a different kind of movement disorder. At first it can be hard to tell the difference between tics and chorea. It is thought that around one in five children will have at least one relapse over time, although the true number may be much higher. It is rare for relapses to occur in adulthood, however this may occur during pregnancy or with the use of the oral contraceptive pill.
Little is known about the long-term effect of Sydenham’s Chorea on behaviour and mood. In the majority of cases, the young person will make a full recovery after about two years. We know however, that some children may experience behavioural and emotional changes that require on-going support from the Child and Adolescent Mental Health Service.

**What are the long-term effects of Sydenham’s Chorea?**

Each child varies in the long-term effects of Sydenham’s Chorea. Many children go on to make a full recovery, whilst others may experience relapses in their symptoms, particularly the movement disorder. As with all serious illnesses, it is important to accept that recovery may take some time and a child may be fatigued or distressed as a consequence of their illness. Some children may go on to develop tics and/or emotional and behavioural problems, and in some cases these may last until they are adults. Some children may require support from the Mental Health services for a short while and in some cases there may be a need that continues over time.

We know that adults who had Sydenham’s Chorea as a child are at an increased risk of developing cardiac difficulties, particularly valve abnormalities and heart failure, and may require on-going support and medical treatment for this.

**Does Sydenham’s Chorea always come with Chorea Gravidarum?**

No. Chorea Gravidarum is a movement disorder that may occur during a pregnancy. It is thought that around 20-40% of young people with Sydenham’s Chorea may go on to be affected by Chorea Gravidarum, which is when the pregnant woman displays involuntary movements including abrupt jerks and movements of the limbs, along with facial grimacing.

**What is the best way to treat Sydenham’s Chorea?**

A child with Sydenham’s Chorea is first treated with antibiotics, usually Penicillin. This is to treat any Streptococcal infection that is present. The child will be required to remain on Penicillin until they are eighteen years old, and this is advised to protect against inflammation of the heart.

Children with chorea may benefit from advice from an Occupational Therapist or a Physiotherapist, as there are various aids and adaptations that can help to minimise the effects of the movement disorder, while it lasts.

If the movement disorder is problematic and impacting on the child’s day to day functioning, a Paediatric Neurologist, who will consider using medicines to help settle the chorea, may see the child. All medicines for movement disorder have side effects and there is no completely reliable treatment, but various drugs may be helpful. In severe cases of Sydenham’s Chorea, there may be consideration of treatment to reduce the activity of the immune system, but this is not a routine approach.
Problems arising in the months after the acute illness will need to be assessed and treated according to the assessment at this time.

**Can Sydenham’s Chorea persist for decades?**

Most children with Sydenham’s Chorea will be free of the condition within their childhood. This is a complex disorder and there are changes that arise as part of the condition which may continue in to adult life. Chorea usually settles but there are risks linked to the oral contraceptive pill and to pregnancy (Chorea Gravidarum). A small number of children have some persistent motor symptoms. These may be tics that are brought on by the chorea, rather than the initial type of movement disorder.

The emotional and behavioural effects of Sydenham’s Chorea can change a person’s life. Sometimes there are persistent changes in the brain that can be shown on a scan, but in other cases the process is more subtle. Not all change is a bad thing. Some people believe that Jane Avril, a famous dancer in Paris in the nineteenth century, became successful because of the impact of “St Vitus Dance” (or Sydenham’s Chorea) on her life.