

Dental Splints – Results from the Tourettes Action Survey

We've heard from several people about the use of dental splints to treat Tourette Syndrome. This therapy has not been clinically trialled and therefore we cannot say with any certainty whether or not it is effective. A full clinical trial is now being planned by the Tourette Syndrome Association, USA. We are in close contact with them and will report the findings to you as soon as they become available. Treatments for TS are always difficult to assess without this kind of scientific data and unfortunately early encouraging results can turn out to be unsustainable or due to chance.

Over the past few months, we have collected responses on a survey designed to find out more about splints and whether the people who have them have had success.

Below are the findings from two surveys – one from the members who have had the therapy and one from the dentists we know of who are offering it. Please note that this is not a 'scientific' document but just for information purposes only.

Summary of the Questionnaire to our Members

The survey was comprised of 21 questions designed to find out more about the circumstances of individuals who have had the dental implant treatment. In total, 7 people completed the survey. This is a small number but we have some interesting results and we will continue to collect information from members and dentists who are willing to join the survey. For confidentiality purposes, we cannot disclose any personal information.

Background Information

The majority of people who have tried the treatment were aged under 15 and all were male. Five out of the seven people reported to have pure Tourette's, the remaining two had Tourette Syndrome and other conditions (such as OCD and Autism Spectrum

Disorder.) All had received a formal diagnosis of Tourette's from a specialist and three of the respondents were taking medication.

Impact of Tics on Daily Life

The participants reported that the majority of tics affected their face, head and neck, with several people also reporting coprolalia. As expected, tics tended to effect people differently, with some people reporting only mild impacts on their daily life, whereas others reported major difficulties in self-esteem, family life, social acceptance, or school or job problems.

The Dental Splint

Four out of the seven respondents reported that their dentists told them the treatment would completely cure them. One person was not offered a complete cure and the remaining two people were told that there was a chance of success but this could not be guaranteed. On average, between 2 and 3 visits to the dentist were required, although sometimes this was much more and in one case was as high as 24 (monthly appointments for two years). None of the dentists discussed the treatment with the person's doctor or specialist.

The majority of participants received the therapy within the last 12 months, although one respondent received it several years ago. In terms of the effectiveness of the splints, two people were reasonably happy (most of the tics disappeared but some remained), one person was satisfied (approximately half of the tics disappeared but the other half remained), two people were completely dissatisfied (all of the tics remained) and two other people reported that it was too early to tell whether the splint was effective due to complications in the splint adjustment. None of the participants were completely cured / tic-free.

One of the respondents reported that the splint also had a positive effect on their OCD, however another person reported a side effect with difficulties holding their jaw in the new position.

The cost of the therapy ranged from £3600 to over £10,000. This treatment is only available privately. We have heard informally from the US that the cost of the treatment there is around \$3000. The NHS would be very unlikely to offer the treatment unless is shown to be effective in a rigorous trial of the kind planned in America.

Summary of the Questionnaire to the dentists

The survey to the dentists consisted of 14 questions designed to find out more about what therapies they offered to people with TS. We are currently aware of four dentists offering splint therapies – three of them responded to our survey and we would be very happy to hear from others.

Background Information – how the splints work

Part of the problem is that Tourette doctors find it hard to explain how dental treatments could be effective on the basis of our current understanding of the neurobiology of TS. The dentists were asked how the splints work. They responded with the following comments –

“Tourettes is linked to a temporo-mandibular jaw dysfunction. This is almost always without exception. If the lower jaw is too far back and the joint is compromised, then the disc displacement can cause pressure on the auriculotemporal nerve. This can have a cross connection effect on the optic nerve (eye blinking), the glossopharyngeal nerve (throat clearing, barking, coprolalia) and the accessory nerve (shoulder shrugging, twitching)...”

“The treatment is to reduce and remove this compression by the lower jaw being too far back. This starts with splint therapy to bring the lower jaw down and forward to stop the compression. It also requires upper arch expansion to house the lower jaw in the new position and this requires advanced orthodontic finishing...”

“The splint has to be set at a very specific vertical height in order to reduce and eliminate tics...”

Collectively, the three dentists have treated 19 patients, 8 of these under the age of 17. A minimum of three visits to the dentist were deemed necessary to complete the therapy, however patients may need to be seen on an ‘as and when’ basis for several

months or years. One of the dentists reported that 24 visits were required (follow up therapy for two years at monthly intervals).

The dentists reported that they charged from £2500 (in basic cases) to over £10,000.

Effectiveness of the splint

The dentists were then asked to rate the effectiveness of the splint in terms of reducing tics. One dentist reported that in one patient, the symptoms completely disappeared. However, in the majority of other cases, most of the symptoms disappeared but some remained.

None of the dentists reported that the therapy was totally ineffective. This somewhat contradicts the reports from our members, some of whom reported that there were no beneficial effects at all. The dentists did not use any formal method of assessing tics before and after the therapy of the kind that will be necessary in the trial being planned in America..

When asked about the long term effects of the treatment, two of the dentists reported that there were continuing beneficial long-term effects of the splint (i.e. the therapy did not 'wear off' after a while). However, one dentist reported that a patient developed an oral tic after the therapy but there were no additional side effects. When asked about the effect of the splint on other conditions in addition to TS, a beneficial effect was reported on ADHD and anxiety.

None of the dentists felt it necessary to liaise with the patient's doctors or specialists.

Conclusion

We believe that there is insufficient evidence to say whether or not dental therapies work and the idea is not based on theories that link well with our increasing understanding of the cause of TS. For this reason the results of a proper clinical trial will be very important in clarifying the situation.

There are a couple of features which we find concerning. Firstly, in medical practise doctors would feel it necessary to communicate amongst the team looking after a patient whereas dental treatment is being offered in isolation. Secondly it would appear that some families are being told that a complete cure is expected from the treatment- TS is never that predictable and this claim is clearly unrealistic. As many of the patients are adolescents it is worth also remembering that TS symptoms tend to improve spontaneously around that time in many people.

These results are preliminary due to small numbers and more importantly we await the trial from America that will likely be some time in coming. We will keep members informed about progress in this field and if our own survey becomes bigger.

If you are thinking of trying dental splints, we hope that knowledge of the current status will help in your decision. If you go ahead please do consider contacting us to take part in the Tourettes Action survey. If you require any further information, please contact [Andy](#).