

Removing Neurofibromas

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Most neurofibromas can be removed.

If you have neurofibromas that are causing you distress, you may elect to have them removed. They are often, but not always covered by insurance, Medicare and Medicaid with proper physician documentation.

However, it is **VERY** important to seek a plastic surgeon or a dermatologist that has experience with neurofibromatosis and the removal of neurofibromas. Neurofibromas do not act like other benign tumors or “skin tags”. Most neurofibromas have a deeper component than what is seen on the skin. Also, they can exert a hormonal effect on surrounding tissues including a tendency for greater bleeding. The scarring, bleeding and complications can be more serious and vary from patient to patient.

Also, there are different types of neurofibromas and it is important that the surgeon knows what type they are removing. Some may be difficult or impossible to remove and may cause permanent nerve damage or a hematoma. Again, having a plastic surgeon with experience and knowledge in NF is vital!

We also recommend that you consult with your NF specialist before proceeding with the removal of any neurofibromas.

Disclaimer

While there are a number of different techniques which have been shown to be effective in removing different types of neurofibromas, all surgeries have risks, including general anesthesia. This includes the techniques described below. This article DOES NOT take the place of medical advice given by a physician, and we urge those contemplating removal of neurofibromas to talk to their NF doctor first and to proceed cautiously.

There are many ways to remove neurofibromas.

There are many different ways in which neurofibromas may be removed. It usually depends on the type, location, and size of the tumor and the preference and experience of the surgeon. Usually a neurofibroma is “excised”, meaning “cut out”, by a scalpel or other means; or they are “destroyed” by electrosurgery. The tumors may also be destroyed (ablated) by desiccation (dehydration or drying), or vaporized using electrosurgery. The type of technique used largely depends on the size, location, and number of tumors being treated.

If a surgeon is removing several small neurofibromas (let’s say 1 to 15), they may use a scalpel and perform a simple excision. They may also use some form of electrosurgery which destroys the tumors instead of a traditional excision.

Larger or more extensive neurofibromas (eg, plexiform neurofibromas) require excision using a scalpel and closure rather than electrosurgery.

In patients with hundreds of dermal neurofibromas on the skin, simple excision is not practical. Because the neurofibromas will most likely vary in size, location and depth, the surgeon may use a combination of excision and electrosurgery techniques.

One of the more popular electrosurgical techniques is electrodesiccation. Electrodesiccation is a procedure where a device is used to apply an electrical current to neurofibromas. Hundreds of tumors can be treated this way. This procedure dehydrates the tissue with which it contacts and can penetrate deeper than other methods of cauterization. Surgeons may also use *fulguration* and *electrocoagulation* for more superficial neurofibromas. Overall, to effectively treat the deeper portions, electrodesiccation is believed to hold the greatest benefit, although not as effective as traditional surgical excision using a scalpel.

It is important to note that no form of electrosurgery, excision or any other form of treatment will stop the possible continued slow growth of new skin tumors, even tumors adjacent to the treated areas. Also it is possible that, depending on the experience of the surgeon, the neurofibromas may not be completely excised or destroyed by electrodesiccation and these recurrences may need to be retreated. Surgery should improve skin contour by eliminating the polyp-like masses that protrude. There are certain neurofibromas that may have extension down into the fat layer of skin and can travel in all directions. Complete excision of these tumors cannot be guaranteed with any available technique, including surgical excision, because of the infiltrative nature of neurofibromatosis.

Most plastic surgeons and dermatologists do “electrodesiccation”, but there are only a few plastic surgeons in the US who have experience using electrodesiccation in conjunction with other techniques to remove neurofibromas in high quantity. These surgeons may remove **hundreds** of dermal neurofibromas at a time. While the NF community commonly describes this as “electrodesiccation”, it is important to understand whether the surgeon is aware of the differences with other electrosurgical techniques. Instead of asking a surgeon whether he or she performs electrodesiccation, it would be better to ask if he or she does ***electrosurgical removal of neurofibromas in high quantities under general anesthesia (ESR of NF1 HQ under GA)***.

Insurance Issues and Coding

When a doctor bills an insurance company, Medicare or Medicaid, they must provide a procedure code called a CPT[®] code. CPT codes are established by the American Medical Association. The insurance companies work together to establish what they will pay for each procedure.

There are several different codes that may be used for the removal of neurofibroma depending on the type of procedure used and for how many are being removed. The most commonly used codes are below. They are more appropriate for the removal of less than 50 lesions.

CPT Code 17110 for the **destruction of up to 14 lesions** using destructive techniques such as laser surgery, electrodesiccation, electrosurgery, cryosurgery, chemosurgery, surgical curettement

CPT Code 17111 for **15 or more lesions** using destructive techniques such as laser surgery, electrodesiccation, electrosurgery, cryosurgery, chemosurgery, surgical curettement

CPT Code 64788 for **excision** of neurofibromas using a scalpel

CPT Code 64790 for **excision** from a peripheral nerve

CPT Code 64792 for **excision** of neurofibroma extensive (including malignant type)

Unfortunately, these codes don't adequately reflect the technique of electrodesiccation or the *electrosurgical removal of neurofibromas in high quantities* where **hundreds** of neurofibromas are removed during one session. Again, this technique is not widely practiced by plastic surgeons.

When the technique is used it may be coded under 64792 but this code refers to "excision" and not electrosurgical destruction of tumors. Also, the term "extensive" is vague. Occasionally, an insurance company may insist a patient seek treatment with a local doctor who they believe performs high volume removal of neurofibromas because the doctor has used the code 64792 in the past. When the patient does follow through with the referred doctor, the medical advice given is that they will only remove a few.

New CPT Codes

NF Midwest has been working for years to clarify what "electrodesiccation" and the high quantity removal of neurofibromas constitutes, in order to improve understanding and awareness of the procedure among the NF community. In 2014, we started working with Dr. Taylor, a parent of an adult with NF, to push for clearer CPT codes. Dr. Taylor petitioned the American Medical Association (AMA) for additional codes. After three attempts he met with success!

Beginning January 1st, 2016 there are two new procedural codes that surgeons will have to use when appropriate for the **extensive destruction** of neurofibromas. Destruction includes electrosurgical techniques that "destroy" the tumor, not excision techniques that cut the tumor out.

These new codes are temporary (Category III) codes. They are used to collect data in order to see how necessary they are and will be in effect until December 31, 2027 (extended from 2021). These codes will be added permanently to the CPT code listing if they are found to be useful and used by **at least** 30 different surgeons during the six-year period. Below are the new codes.

CPT Code 0419T for the destruction of extensive (greater than 50) cutaneous and subcutaneous neurofibromata (neurofibromas) of the face, head and neck.

CPT Code 0420T for the destruction of extensive (greater than 100) cutaneous and subcutaneous neurofibromata (neurofibromas) of the trunk and extremities.

This is HUGE, but it is still only the beginning.

While the correct coding will be required, there is no way to know what value insurance companies, Medicare, and Medicaid will assign. It is hoped that they will at least pay in the way that they have been for the ambiguous codes that have been used in the past.

How to Get Hundreds of Fibromas Removed

Currently, we have identified five experienced plastic surgeons (we know there are others) that perform *electrosurgical removal of neurofibromas in high quantities under general anesthesia (ESR of NF1 HQ under GA)*. These surgeons are:

Hubert Weinberg, MD	917-492-4200 New York, NY www.hweinbergplasticsurgery.com
Jason Ko, MD	312-695-6022 Chicago, IL www.jasonkomd.com
Andre Panossian, MD	310-275-5086 Beverly Hills, CA www.drpanossian.com
Juliana Hansen, MD	Oregon Health Sciences U Portland, OR
Joel Solomon, MD	Oregon Health Sciences U Portland, OR

The NF community needs more. If you have, or know of a surgeon that you believe does *ESR of NF1 HQ under GA* in that way that has been commonly referred to as “electrodesiccation” please let us know. If you are interested in having this procedure but can’t get to any of the surgeons above, contact your NF clinic and let them know of your interest. If you can’t get to an experienced plastic surgeon and feel it is absolutely necessary to find someone locally, use this paper to describe the procedure. If they are interested we can try to connect them to one of the doctors above for more information.

Important Note

Some of the information and requirements regarding the new CPT codes are still being clarified. The information contained above will most likely be changing and will be updated as we go. If you are interested in this information, please make sure we have your email or check our website for updates.