



## Therapeutic Plasma Exchange Series

### *Talking to Your Doctor About Therapeutic Plasma Exchange*

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#### **Background**

If you have been reading about therapeutic plasma exchange (TPE) for the treatment of systemic scleroderma on this website or elsewhere and have decided that you would like to discuss this potential treatment approach with your doctor, this article is written to provide you with background information that may be useful in these discussions. First, it is important to understand that the Scleroderma Education Project does not endorse or recommend ANY treatment option. It is our belief that individual care decisions should be made based on informed discussions between patients and their team of clinicians. Our focus is to help you to become informed about TPE to help to facilitate productive discussions with your doctors about this potential treatment approach.

One other general comment: since there are no FDA approved treatments for scleroderma, any treatment used to treat this disease, whether immunosuppressants like methotrexate, Cellcept, or Cytoxan, or alternative approaches like TPE, is an “off-label” use of that treatment. However, clinicians are much more accustomed to using immunosuppressant drugs to treat scleroderma. Typically, the main doctor involved in treating patients with systemic scleroderma is a rheumatologist, often working with specialists such as pulmonologists or gastroenterologists who are focused on dealing with specific symptoms that commonly arise in conjunction with systemic scleroderma. Unfortunately, rheumatologists have little experience with TPE since it is typically not used for the types of diseases they usually treat. This means that one of the key steps/challenges in initiating discussions with your doctor about TPE will be the need to educate your doctor about TPE in addition to educating yourself. Therefore, anyone who is thinking about trying TPE will need to be fully educated about the treatment to be able to advocate for her/himself when talking with her/his doctor.

#### **Step 1: Educating Yourself About TPE**

Here is what we recommend you do/read to educate yourself about plasma exchange:

- **Watch our educational video on therapeutic plasma exchange.** While this is targeted at clinicians, it is easy to understand. Here is the link:

<https://youtu.be/iWT0oW8FRdE>

- **Therapeutic Plasma Exchange for the Treatment of Systemic Scleroderma: A Comprehensive Review and Analysis.** Download and read the review that was published in the Journal of Scleroderma and Related Disorders in June 2018. Since it is published Open Access, the PDF version of the article can be downloaded at no cost.

This paper may contain some medical terminology that you may not fully understand, but most of it is very straightforward. You probably don't need to study all of the tables in detail, but you might want to scan them to get a better idea of the research that was reviewed for this paper. Here is the link to the publisher's website where you can download the PDF:

Link to publisher's website: <http://dx.doi.org/10.1177/2397198318758606>

- ***Successful Long-Term (22 Year) Treatment of Limited Scleroderma Using Therapeutic Plasma Exchange: Is Blood Rheology the Key?*** Download and read the long-term case report that was mentioned on the video and in the review paper. This is the only published research study that followed a patient using this approach as the sole treatment over a very long time period (22 years). Here are links to the manuscript version of the paper in both US and A4 formats (the published version cannot be accessed without paying a fee):

US Format: [sclerodermainfo.org/pdf/CHM-US.pdf](http://sclerodermainfo.org/pdf/CHM-US.pdf)

A4 Format: [sclerodermainfo.org/pdf/CHM-A4.pdf](http://sclerodermainfo.org/pdf/CHM-A4.pdf)

- ***Suggested Guidelines for a One-Year Trial of Therapeutic Plasma Exchange as a Treatment for Systemic Sclerosis.*** This document will give you a good idea of what will be done if your doctor decides to do an individual trial of TPE using these guidelines as the basis. Our hope is to turn these one-year trials into a case series that can help to advance research on therapeutic plasma exchange as a treatment for systemic scleroderma. Here are the links:

US Format: [sclerodermainfo.org/pdf/TPE-Guidelines-US.pdf](http://sclerodermainfo.org/pdf/TPE-Guidelines-US.pdf)

A4 Format: [sclerodermainfo.org/pdf/TPE-Guidelines-A4.pdf](http://sclerodermainfo.org/pdf/TPE-Guidelines-A4.pdf)

- ***Therapeutic Plasma Exchange: a Guide for Newbies.*** This article explains what it is like to have a therapeutic plasma exchange treatment, and helps to prepare you for a successful experience with this treatment approach. Here are the links:

US Format: [sclerodermainfo.org/pdf/TPE-for-Newbies-US.pdf](http://sclerodermainfo.org/pdf/TPE-for-Newbies-US.pdf)

A4 Format: [sclerodermainfo.org/pdf/TPE-for-Newbies-A4.pdf](http://sclerodermainfo.org/pdf/TPE-for-Newbies-A4.pdf)

- (Optional) Read two articles from the Research section of the Scleroderma Education Project website (<http://sclerodermainfo.org/research/>). One is a disease model for systemic scleroderma. The other article discusses the background research behind therapeutic plasma exchange, focusing primarily on the research that scleroderma patients have abnormal blood that is unusually "thick." These are very technical articles, but you should be able to understand most of the information in them.

If you have questions about any of these articles, please feel free to contact us directly at [info@sclerodermainfo.org](mailto:info@sclerodermainfo.org) or by posting a comment on the Scleroderma Education Project website (preferred).

## Step 2: How NOT to talk with your clinician about trying therapeutic plasma exchange

Over the past several years, mostly before the TPE review paper was published, a number of patients have tried to talk with their doctors about trying TPE, often experiencing a quick, negative reaction. Some of the common responses from clinicians included:

- TPE is too dangerous.
- They tried it a long time ago, and it didn't work.
- It's way too expensive.
- You can't do long-term TPE without having a surgically installed access port.
- TPE is too new and experimental! (My personal favorite – TPE has been widely used for almost 40 years.)

(Out of all of these comments, the only one that is partially valid is the fourth bullet. Currently, the research literature suggests that with long-term TPE, about 25% of patients will eventually need a central port for venous access. However, with modern techniques for venous access, that figure should drop significantly in the future.)

So, any discussion that basically starts with - "Dr. xxx, I have been reading about therapeutic plasma exchange as a treatment option for scleroderma in my Facebook support group. Can I try that?" - will almost always get shot down immediately for the reasons listed above. It is important to realize that most scleroderma researchers and clinicians are completely unfamiliar with the published research literature on therapeutic plasma exchange. Here is an excerpt from a comment on TPE by a member of the Scleroderma Foundation Medical Advisory Board in June 2014 (emphasis ours). Note that the term "plasmapheresis" is commonly used interchangeably with "therapeutic plasma exchange", although it is technically a slightly different procedure:

*Plasmapheresis is a procedure where the plasma component of blood is removed and replaced with plasma from blood donors. It is used in the treatment of hyperviscosity syndromes which are associated with blood disorders and which are very different from scleroderma. Plasmapheresis is occasionally used in the treatment of some rheumatologic conditions as well. One small open label trial looking at whether plasmapheresis had utility in scleroderma was performed and published in 1991 and showed some improvement in Raynaud's and digital ulceration with plasmapheresis.*

Since our recently published comprehensive review included 46 published studies, you can see there might be quite an educational gap to bridge in bringing up a topic such as therapeutic plasma exchange with your physician!

## Step 3: How to actually talk with your doctor about trying therapeutic plasma exchange

After consulting with a number of clinicians about this, including members of our own Medical Advisory Board, we think that the best way to start this dialog is that after you have read and understood all of the background research discussed earlier, launch a conversation similar to the example below (rephrase this in a manner that would be more your own personal style).

That is probably best done at a regular appointment, but could potentially be done by email/MyChart communication.

Dr. x. Would you be willing to read a research study recently published in the *Journal of Scleroderma and Related Disorders* about a treatment approach for scleroderma that may be of interest to you? I would like to discuss this approach with you, because I think there's a chance it could work in my situation.

As a side note, if your doctor answers this initial question with “no,” then you may want to consider migrating to a doctor who is at least open to learning something new...

Likely response (hopefully):

Of course. I am always willing to look at research that is published in a major peer-reviewed journal. What treatment are you talking about?

Your response:

The treatment is the administration of therapeutic plasma exchange in a special pulsed protocol. This is described in detail in one of the documents I have printed out for you. A comprehensive review of the research literature on the use of therapeutic plasma exchange to treat systemic scleroderma was just published in the *Journal of Scleroderma and Related Disorders*. I read the paper and several other related articles, and I would like to discuss this potential treatment approach with you after you have had a chance to read these papers.

This is where things will get interesting/unpredictable. If the doctor dismisses this, it is not unreasonable to be assertive and indicate that the recently published paper reviewed 46 studies that included 455 patients treated with TPE. All you are asking the doctor to do initially is to read *one* published research study, which would not seem to be an unreasonable request.

### **Step 4: What to give to your doctor**

Assuming you reach this point, here are the three documents that we suggest you print out and give to your doctor. The links to all three of these documents are included earlier in this article.

- **Therapeutic Plasma Exchange for the Treatment of Systemic Scleroderma: A Comprehensive Review and Analysis.**
- **Successful Long-Term (22 Year) Treatment of Limited Scleroderma Using Therapeutic Plasma Exchange: Is Blood Rheology the Key?**
- **Suggested Guidelines for a One-Year Trial of Therapeutic Plasma Exchange for Treating Systemic Sclerosis.**

We strongly recommend printing these documents double-sided, even if you have to print them at a friend's house or an office supply store. The review paper alone is 21 pages long when printed. Doctors are very busy and will be more resistant to reading a “big” document than a smaller one (and it saves trees).

We suggest you “package” these documents as follows:

- The TPE Review paper should be the first document.
- Put the case report and Suggested Guidelines documents into an envelope labeled “Additional Articles on Therapeutic Plasma Exchange”.

When you give these documents to your doctor at a visit or drop them off at her/his office after an email exchange, you should book an appointment with the specific purpose of talking about TPE after the clinician has read the information you provided to her/him. You should try to be completely prepared to discuss any of the concerns that the clinician might bring up at that follow-up meeting. Please note that you should feel free to inform your doctor that s/he can feel free to contact me for additional information at any time.

My contact information is:

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