Scleroderma Foundation Michigan Chapter's

Guide To Organizing Your Health Care With Index Cards

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No Known Cause.
No Known CURE.
Together, WE CAN Change That!
It All Begins With You!

Be the Best Health Care Advocate You Can!

Whether you have scleroderma, an overlapping autoimmune disease or you are caring for a loved one who is ill, it is important to become a strong health care advocate.

In this manual, you will learn the following:

- the importance of organizing medical records
- how to categorize all your doctor's visits
- the best way to keep your prescription information in one area
- the procedure for maintaining documentation on all your lab results
- how to document all of your x-rays and other procedures
- why you need to create a personal medical health care documented profile

The medical information in this manual is provided as an informational resource only, and is not to be used or relied on for any diagnostic or treatment purposes. Please consult your health care provider, if you have any specific questions regarding your medical condition, concerns toward your loved one, or if you think you are having trouble coping with your disease.

The Scleroderma Foundation expressly disclaims responsibility, and shall have no liability, for any damages, loss, injury, or liability whatsoever suffered as a result of your reliance on the information contained in this manual. The Scleroderma Foundation does not endorse specifically any test, treatment, or procedure mentioned in this manual.

The Importance of Organizing Medical Records

Organizing your medical information does not need to be overwhelming and in fact can be done easily. The first step in this process is to determine what method is best for you to use to keep track of your medical records. Are you someone who likes to use the computer and feel confident that storing this type of data can be done securely and safely? If you do use a computerized method, you will need to consider what type of back-up system you have in place to assure that all of your documentation is safe in case you're computer crashes and the hard drive is not retrievable.

If you are someone who is not comfortable with computers, or you do not have access to your own computer system, you can purchase 3 x 5 index cards or even a three ring binder to organize and store your medical information. If you select this option, you will want to make sure that you have a fire proof storage location in which you can store this when you are not using or referring to these items. This will assure that they are safe and available to anyone in your family who may need them in case of an emergency.

If you decide to use 3 x 5 index cards, you will need to purchase a store container for them, much like a recipe box. They are typically plastic and are called 3 x 5 index card file and they come with built in notches to hold the index cards up right so they are easily read while they are in place. Index cards come with lines on them or plain depending on your specific desires and needs. You can also purchase 3 x 5 cards in different colors if you decide you want to color code the different sections to make it easier to remember how to find things. If you are looking for something different, you can also purchase a larger unit that will hold 1,000 index cards and it is a snap and storage index file option that can be found at most local office supply stores or on-line.

Organizing Medical Records

Making Your System Work for You

Now that you have your method for organizing your documentation selected, you can move on to the next step in this process, categorizing the subtopics of your documentation. This is going to vary from patient to patient but here are some suggestions that you might find helpful as you begin to sort through your records.

Doctor Information

Medications

Pharmacy

Pathology

Lab Reports

Treatment Care and Plans

Future Medical Care

Insurance Information

Bills

Power of Attorney

Living Will

Advanced Directives

Medical To Do List

Doctor Information

Maintaining proper and accurate information about all of your physicians is very important especially when you or your loved one requires the care of multi disciplinarian areas of health care.

The easiest way to maintain accurate and updated records is to take a business card from the office when you have your first visit and to log the information into your secured computer system or on a 3 x 5 index card or whatever organizing method you have set up for yourself.

You will want to include the following information for each doctor that you see, whether you continue to see the doctor or not. The reason for this is simple, you never know if you will return to this office in the future or if you will need to obtain any of your medical records from them and you will want to have the office information in your file so it can be accessed easily.

Information to maintain for all of your physicians:

- Complete name (do not just include last name since there can often be multiple doctors with the same name and if your doctor moves it can be difficult to locate if you do not remember his/her compete name.)
- Complete address of all offices – also updated address if there have been moves. This helps keep track if you need past records. Remember to include suite numbers to make it easy for loved ones to find the location if needed. Complete documentation makes it much easier for others to move forward in the event you are unable to be your own health care advocate.
- Telephone number for all offices
- Fax number – this is especially important because you may need to provide this to your pharmacy or to other physician's office.
- Hours of the office
- Type of care provided
- Date you began your care with office

Sample 3 x 5 Card

Doctor Information

Dr. John F. Smith

Current Adress:

23111 Park Avenue
Lake Pointe Drive, MI 48111

Past Address:

15672 Hart Lane
Livonia, MI 48150

Phone: (248) 561-5670

Fax: (248) 561-7980

Hours: M/T/W/TH 8:00 – 4:00 Fri 8:00- 1:00

Care: Primary Care/ Internal Medicine

Date of Service Began: 2/5/2020

Notes: Vacation every July. Wants me to have a yearly physical with blood work.

Medications

Keeping track of your medication does not need to require much of your time if you do it on a regular basis and you stay organized. Maintaining good documentation regarding your prescriptions will help not only you and your loved ones keep track of what you are putting into your body, but it can also become useful information to other physicians you may need to see.

The best way to document your prescriptions is to write down the information every time you obtain a new medication from a doctor or if one of your medications is changed. This way your records will remain accurate and they will always be updated in case of an emergency.

It is also a good idea to date any updated information so that anyone who is referring to this information has a point of referral to provide a health care professional with if needed. It may be important for a physician to know that a patient began taking a higher dosage of a specific medication three months ago verses two weeks ago. The more information you or your loved one can provide a doctor with regarding your health, the better picture the doctor will have as to why you are displaying certain symptoms, your body is reacting a specific way or a medication is possibly not working the way the doctor had hoped it would.

Think of yourself as an artist and your records as the canvas, you want to paint the most complete picture that you can for each physician that you see, every time that you see him or her. By recording all of your medical information correctly every time, you are taking incredible steps toward the right direction of managing your health care.

Good information to include for each medication you take includes:

- drug name
- dose you take
- time you take medication
- is medication taken with or without food?
- date you began taking the medication
- name, address, phone number and hours of pharmacy that holds the prescription
- number of refills and date it expires
- include over the counter vitamins and supplements in your record keeping as these also can play a role in your health

Pharmacy

Many patients establish a good working relationship with their pharmacist and are able to ask him or her questions about the medications that they are taking. It is beneficial when a patient or loved one has this type of relationship because it can provide the educational information needed to keep yourself aware of the potential side effects of the medications you are taking or any possible interactions that your medications may have.

If you use more than one pharmacy to obtain your medications or if you receive your medications from an on-line service, you will want to maintain all that information under this category also.

Things to include under pharmacy are:

- complete name of the pharmacy-do not use any nick names
- address including suites or offices numbers
- phone number
- fax number
- hours the pharmacy is open
- name of pharmacist(s)

Pathology

Keeping track of your pathology can require multiple files if you see more than one doctor and you have overlapping medical conditions. This may sound like it could be time consuming but in fact it does not have to be if you ask for copies of all of your pathology when they are completed.

A good way to do this is to document the following:

- type of pathology completed
- date of service
- doctor who ordered service
- reason pathology was ordered
- results
- notes
- future treatment plans as result of pathology

By keeping all of this information in one secured location, you will be helping to create a history of your medical procedures for yourself, your loved ones, all your current doctors and any doctors you may see in the future.

This will also make it easier for you to complete patient centered forms for any doctor's office you may visit in the future since you will be building a chronological timeline that you can either make copies of or copy from and include the information on doctor's forms.

Lab Reports

As a scleroderma patient or the loved one of a scleroderma patient, you know that your doctor has ordered several labs tests. Keeping track of these tests does not have to be a daunting task; it can in fact be easy!

If you are using 3 x 5 index cards, you can simply create a 3 x 5 card for each lab test that your doctor requires you to have. If you are using the binder method, you will use a separate page for each lab test and if you are using the computer, you can create a separate page for lab reports and include the details on that page.

No matter which system you are using, documenting your results and including the following will be the same:

- type of lab service
- date of service
- doctor who order service
- reason for testing
- results of testing
- future testing required
- notes

Treatment Care and Plans

During regular doctor visits and every trip to a specialist's office, a patient will obtain important medical information. Documenting some of this information will be a good idea. The question is, "What is important to document verses what is not necessary to include in your medical health care history profile?"

To consider what you want to include in your personal medical health care profile, you need to ask yourself a few questions:

- Is this important information that I will need to remember in the future?
- Will I need to share this information with another doctor now or in the future?
- Does this information affect your overall health?

If you answer yes to any of these questions, then you will want to include the information from your doctor's visit or your trip to a specialist's office into your personal medical health care documented history profile.

The next question you may be asking is, "What exactly should I include in my documenting?" This is actually a very good question since going to a doctor's appointment can be an overwhelming experience for many patients. That is why it is often recommended that patients ask a loved one or trusted friend to accompany them. Two sets of ears are much better than one and it is always nice to have someone there to take notes while you are there asking your questions and absorbing what the doctor is telling you. This helps to remove some of the emotional components that often go hand and hand with doctor visits.

You will want to document important things from your doctor's visit within 24 hours of the visit so that they will remain accurate in your mind if you did not take notes while in the office or someone else did not take notes for you. You can also ask your doctor if he or she can supply you with any information for your records that would be beneficial.

When documenting you can do so in bullet fashion to include only the most important facts or in short sentences to keep the process easier. Remember to include only the most important facts and to include as many details as you can so you can remember to let other doctors know your accurate medical history.

Future Medical Care

An area that you might want to include in your documenting might be, your future medical care needs. The reason for this is that it is a good way to keep track of what your future medical needs are and this can provide you, your loved one and anyone who may be viewing this documentation in case of an emergency a clear idea of what your physical and mental needs look like. It also once again becomes part of your personal medical health care documented profile. All of these items are like your own quilt of life and are necessary to give your medical team a clear view of YOU!

Items to include in this documentation could be:

- dental care plans for the future
- medical plans for the future
- mental treatment plans for the future

Insurance Information

Including your insurance information in your personal medical health care documented profile can seem like an odd concept since you carry your insurance cards with you in your purse or wallet. The reason this is being suggested is because this information is critical for others in case you are involved in an emergency, and in the event they cannot locate your insurance cards, they become lost or they are stolen and you need to reference the numbers.

The best way to include your insurance information is to make a copy of the front and back of your cards or to scan them into your computer if you have a secured system. You can also provide a loved one with copies of them that can be placed in a fireproof box or safe in the event of an emergency.

Bills

Another section you can include in your personal medical health care documented profile is bills. In this area you can document the following information:

- date of the bill
- amount of the bill
- service provider
- what the bill was for
- how much insurance paid for
- other important information

You can decide to simply make a copy of the bill and include it in your documentation. This will help your family in the event they take over your finances at any time. It will also help you maintain a clear record of what you have paid and what needs to be paid year after year.

Medical Power of Attorney

In the state of Michigan there are two different types of advance directives.

- Durable Power of Attorney
- Do Not Resuscitate Declaration

A Durable Power of Attorney can be used in inpatient and ambulatory settings.

The Do Not Resuscitate Declaration can be used in settings other than hospitals.

It is very important if you have an advance directive that the following is done:

- complete an advance directive legally
- make sure it is done completely and that is filled out correctly
- clearly consider all of your options and wishes before doing an advance directive
- have the original remain with your attorney
- provide a loved one or trusted friend with a copy
- keep 3 to 5 copies in your personal medical health care documented profile
- know that if you move from state to state your advanced directive may not be legal and may require changing

Living Will

A living will is a specific type of an advance directive in which a person states his or her wishes about medical treatment should he or she be at the end of life and unable to communicate in a formal manner. This formal documentation when done legally becomes what is known as a living will.

Living wills can also be known as "directive to physicians", "health care declarations," or "medical directives."

A living will is created to guide family members and doctors in deciding how aggressively to use medical treatments to delay death of a patient. It serves as a guide to the wishes of a patient.

Michigan does not have a statute governing the use of living wills.

It is very important if you have a living will that the following is done:

- complete a living will legally
- clearly consider all of your options and wishes before doing a living will
- before doing a living will speak to an attorney and determine if it is the best option for you legally and medically
- have the original remain with your attorney
- provide a loved one or trusted friend with a copy
- keep 3 to 5 copies in your personal medical health care documented profile
- know that if you move from state to state your living will may not be legal and may require changing

Advanced Directives

It has become very confusing with so many terms being used in the world of wills and directives. An advanced directive is a general term that describes two kinds of legal documents, living wills and medical powers of attorney.

Both documents provide an individual with the opportunity to dictate the type of medical care he or she desires to receive or if there are specific types of procedures or medical care that an individual does not want to receive or is unable to receive due to religious or personal beliefs.

An advanced directive is created to guide loved ones and medical professionals in the event a patient is unable to make medical decisions due to the inability to communicate or being gravely ill.

The following should be considered in regard to advanced directives:

- complete an advanced directive with an attorney
- clearly consider all of your options and wishes before doing an advanced directive
- before doing an advanced directive speak to an attorney and determine if it is the best option for you legally and medically
- have the original remain with your attorney
- provide a loved one or trusted friend with a copy
- keep 3 to 5 copies in your personal medical health care documented profile
- know that if you move from state to state your advanced directive may not be legal and may require changing

Medical To Do List

The last suggested area that you include in your personal medical health care documented profile is a To Do List. Including this will help to keep you organized in your thought process as well as guide your loved ones and medical professionals should an emergency occur and you are unable to communicate for a short or long time period.

Documenting your medical To Do List is different than future medical care plans. Your To Do List can include the following:

- need to make doctor appointments
- need to cancel doctor appointments
- need to contact insurance company to clarify a bill payment
- desire to do research on a medical topic

Wrapping It All Up!

Creating a personal medical health care documented profile is not something you or a loved one can do in a day. It takes an on-going commitment and willingness to remain organized. Following the steps in this manual will assist you in planning and staying motivated in the process of documenting all of your medical history. In doing this you will help yourself, your loved ones and those in the medical community that treat you.

Becoming the best health care advocate you can be is just a smart decision. It will provide you a sense of control over your health care management. Every decision you make regarding your health will help you get one step closer to feeling as if you are doing something positive for yourself and for your health.

Enjoy creating your own medical health care documented profile. It will serve as a part of your history for generations to come and can be beneficial to your loved ones.

The Scleroderma Foundation encourages scleroderma patients and their loved ones to always seek out a positive attitude in life. The Michigan Chapter is here to assist you by providing resources, education and emotional support. Remember, you are never alone in your scleroderma walk. The Michigan Chapter is here for you! If you would like to talk to a representative of the Michigan Chapter one can be reached at (248) 595-8526.