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Targeting chronic fatigue in Sjögren's Syndrome

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Introduction

Chronic fatigue is a prevalent problem in Sjögren's. About one out of every two patients with Sjögren's is severely fatigued; with major effects on daily functioning.

It seems impossible to explain in a small book how fatigue can be tackled if it has existed for 5, 10, or 20 years. Perhaps you already tried to target this difficult problem yourself or with help from health professionals. Perhaps those efforts were not successful. Nevertheless, this booklet offers advice as to how to tackle fatigue. The basis of this advice stems from results of professional treatment of severe fatigue.

This booklet appears to present a simple solution to this difficult problem. However, it takes time, patience, and perseverance to take steps that can reduce chronic fatigue.

But why shouldn't you try if there is a possibility to reduce your fatigue?



People differ

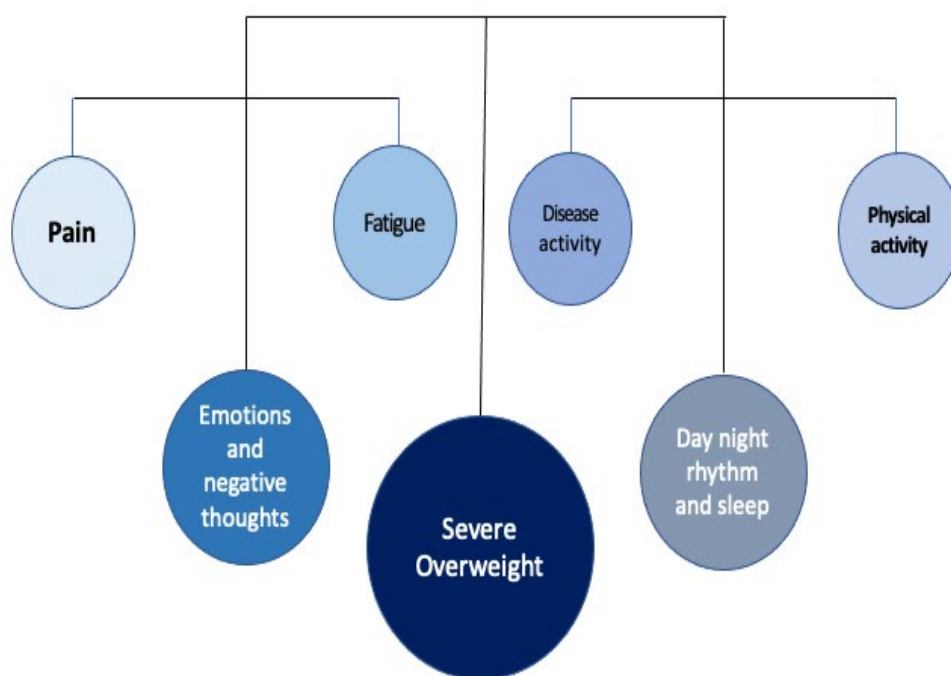
Many factors influence fatigue. These factors can be demonstrated by a hanging mobile toy, a device with stars or other figures hanging from the ceiling (see figure). If one piece moves, all the other pieces move as well. Every individual piece that is a part of the mobile influences the other.

However, every mobile is different. In one mobile, the movements are almost exclusively determined by a single heavy component, while in other mobiles many small components are equally proportioned and determine the movements to the same extent.

The large differences in balance between components of mobiles can be compared to the large variety of influences on fatigue in people. The fatigue in some people is influenced largely by one major factor, while the fatigue in other people is influenced by many interconnected minor factors.



The mobile toy model of chronic fatigue



All factors influence each other. If the position of one factor changes, then the positions of all other factors change as well. In the model shown, 'severe overweight' in particular, has a major influence on all other factors. People differ. For you the model can be very different from the model shown here.

Rank the influences

Everyone must first identify which factor is an especially important influence of their own fatigue. Below are seven factors that can affect fatigue.

Write down these seven factors. Arrange them in an order that applies to yourself. Put the factor that you think influences your fatigue the most at the top. Also arrange the other factors in order from most to least influencing. All factors are discussed in this booklet.

Start reading the sections that advise what can be done regarding the factors that influence your own fatigue most.

Factors that influence fatigue

Arrange these factors. Put the factor which you think influences your fatigue most at the top and the factor that influences your fatigue least at the bottom.

1. Severe overweight
2. Disease activity
3. Day-night rhythm and sleep
4. Physical activity
5. Emotions and negative thoughts
6. Pain
7. Another influence that is not mentioned here

1. Severe overweight

For some people, being severely overweight is the strongest influencing factor of their chronic fatigue. Severe obesity also has an adverse influence on all other factors that influence fatigue: day-night rhythm and sleep, disease activity, emotions and negative thoughts, physical activity, and pain.

To know whether you are overweight, you can use a BMI (body mass index) calculator on the internet. In most countries, people are (if they wish) eligible for (bariatric) surgery that reduces the size of their stomach if their BMI is greater than 35 or 40; especially if there are other diseases such as osteoarthritis or diabetes present. People with severe obesity who want help with weight loss can consult their doctor.



But also with less severe overweight, it is important to reduce unhealthy eating and drinking habits. On-line websites of national nutrition centers generally give good advice. With drastic weight loss, there is a danger that the weight is re-gained later (yo-yo effect). Nonetheless, it is important to reduce unhealthy eating and drinking habits, and to exercise more.

Most people know their guilty pleasures when it comes to unhealthy eating and drinking. A good first step is to list your major guilty pleasures and make a concrete action plan (see next page and back cover). In this plan you will write down which unhealthy food or drinks will be reduced, and to what extent, in the next months.

Beyond good intentions: make an action plan!

Lifestyle changes may alleviate chronic fatigue. To prevent good intentions from failing, it is important to make an action plan that specifies “what” you are going to do “where,” “when,” “for how long” and possibly “with whom” in detail. As an example, we take the goal ‘Losing weight by drinking less alcohol’. An action plan is made.

What?

The action must be specific. For example: “I will not drink any alcohol for at least four days a week for the next six months and a maximum of one glass a day for the other three days. At a party, I can drink a maximum of four glasses of alcohol.”

Where?

It must be clear where you are going to implement the action. The example above specifies how much you will drink at home and at a party.

When?

It must be clear when you will carry out the action. In the example above it is specified for each day.

How long?

Also indicate as precisely as possible how long you want to carry out the action. In the example this is specified for ‘the next six months.’

With whom?

Indicate with whom you will carry out the action. In this example this does not apply. Nevertheless, ask your family members and friends to carry out the action plan.

~~Plan~~

~~Plan~~

~~Plan~~

~~Plan~~

~~Plan~~

Action

2. Disease activity

Sjögren's disease is difficult to treat. An increase of inflammation can increase fatigue. Research in rheumatic and musculoskeletal diseases shows that fatigue decreases after appropriate pharmacological treatment of the inflammatory activity.

- **In case of increased inflammation, it is necessary to consult a doctor.**
- **If the disease activity can be reduced, the fatigue will also decrease.**
- **Any disease must be treated well.**

There is no single substance in the body that provides a clear explanation for persistent (chronic) fatigue. Consequently, there is no medicine that directly targets and reduces chronic fatigue.

Acute inflammation increases fatigue, but it is also a characteristic of rheumatic diseases that chronic fatigue can occur without current disease activity.



3. Day-night rhythm and sleep

Day-night rhythm

The disease process and other factors from the mobile toy model, including chronic fatigue itself, can disturb the common day-night rhythm. Some people live a sedentary life most of the day or they sleep during the day. People who sleep a lot during the day are less likely to fall into deep sleep at night.

Deep sleep is needed for recovery of the body. For example, growth hormone is created during this time. That hormone is needed for a person to have sufficient strength throughout the day. Having a brief nap during the day is not a problem, but really sleeping during the day can reduce the quality of sleep at night. During the night, unless people are awoken often, they do not know whether their sleep is of good quality. This can only be seen by measuring brain activity with EEG equipment.

Thus, a day-night rhythm that is as normal as possible is important. To gain insight into your own day-night rhythm, you can color the diagram on page 12 of this booklet and then discuss it with someone. An example of a completed schedule is shown on the next page. After filling out the schedule, you can decide for yourself whether this is a day-night rhythm that you want and which part of the schedule of activities and rest you would like to change. You can also discuss with a family member or clinician whether your current day-night rhythm is somewhat normal.

If your own schedule shows that the day-night rhythm is not normal or not satisfactory, then make an action plan for a more desirable day-night rhythm and follow that action plan for a long time; at least six weeks. Be patient and persevere. The action plan contains a very concrete description of “what” you will do “where”, “when”, “how long” and possibly “with whom”. For example, when you sleep, watch TV, eat or are active and on the move (picking up the children from school, cycling to the store, and so on).

A completed day-night rhythm schedule by Elise (example)

On the left are the days of the week and above the hours that are spent in a day. The colors indicate what she did. For example, Elise indicates that she had passive relaxation on Monday night before 1 a.m. (colored red). Next, she slept until 7 a.m. (colored blue). The colors blue (sleeping) and red (passive relaxation) predominate in the scheme of Elise. She also slept a lot during the day (blue). The colors yellow and green are rare, and when they occur, Elise experiences those activities as obligations: housework (yellow) and a visit to her sister Friday evening (birthday) and her mother Sunday afternoon (green).

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Mon	Red	Blue	Blue	Blue	Blue	Blue	Blue	Red	Yellow	Blue	Blue	Blue	Red	Blue	Blue	Red	Red	Red	Red	Red	Red	Blue	Red	Red
Tue	Red	Blue	Blue	Blue	Blue	Blue	Blue	Red	Yellow	Blue	Red	Red	Red	Red	Blue	Blue	Red	Red	Red	Red	Blue	Blue	Red	Red
Wed	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Red	Yellow	Blue	Red	Red	Red	Red	Yellow	Blue	Blue	Red	Yellow	Red	Blue	Blue	Red	Red
Thu	Red	Blue	Blue	Blue	Blue	Blue	Blue	Red	Blue	Yellow	Blue	Red	Red	Blue	Blue	Red	Red	Red	Red	Red	Blue	Blue	Red	Red
Fri	Red	Blue	Blue	Blue	Blue	Blue	Blue	Red	Yellow	Blue	Red	Red	Red	Blue	Blue	Red	Red	Red	Yellow	Blue	Yellow	Green	Green	Green
Sat	Green	Green	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Red	Blue	Yellow	Yellow	Red	Red	Red	Red	Blue	Blue	Red	Red
Sun	Red	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Red	Red	Blue	Blue	Green	Green	Red	Red	Yellow	Blue	Blue	Red	Red	Red

- Rest: sleeping
- Passive relaxation: reading, sitting on the couch, watching television, eating
- Active relaxation: walking, cycling, gardening, visiting
- Work/productivity: (volunteer) work, cleaning, shopping


On this day-night scheduel, the days of the week are on the left. The 24 hours of the day are above the schedule.

During the next week, color the schedule at the end of each day (or the following morning). Indicate for each hour with a color what you have done during that hour. Use the colors shown at the bottom of the schedule. After the schedule has been filled in completely:

1. View (and discuss with someone) whether thisis a desired daily routine
2. If desired, change the pattern of sleeping and activities (make an action plan)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Mon																								
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 **Rest:** sleeping

 **Passive relaxation:** reading, sitting on the couch, watching television, eating

 **Active relaxation:** walking, cycling, gardening, visiting

 **Work/productivity:** (volunteer) work, cleaning, shopping

Sleeping

Sleeping better does not mean that more hours are spent sleeping. On the contrary, sleeping better often means that people sleep less hours. It is most important that the quality of sleep is good. That means alternating between deep sleep and light sleep and having fewer periods of wakefulness during the night. On the internet, tips that can help you sleep better can be found everywhere. They are called sleep hygiene tips.

Sleep hygiene tips

1. Sleep-wake rhythm

- Go to bed and get out of bed at the same time every day. Do not sleep too long (maximum 8 hours).
- There is some evidence that a short nap during the day (powernap) can make some people fitter. During a short nap, you doze off for a moment (a minute or so) without sleeping deeply. Avoid sleeping during the day.
- Ensure there is regularity in daily activities.
- Physical exertion during the day is very good, but don't do it
- Exposure to light during the day is very important but avoid exposure to bright light before going to sleep. The hormone melatonin that regulates sleep is sensitive to light.
- Do something relaxing before going to bed (reading a book for example). Watching television just before going to bed can obstruct sleep, because screens of televisions or computers that give blue light suppress the sleep hormone melatonin.
- Before going to sleep, avoid conversations and activities that cause agitation; ask your partner to help you to achieve this goal.

2. Optimal conditions in the bedroom

- Put a glass of water on your bedside table to prevent that you need to get out of bed at night in case of a dry mouth.
- A comfortable mattress and pillow.
- A moderate room temperature (not too cold or too hot) and good ventilation.
- A room that is dark (good curtains) and quiet (use earplugs if necessary).
- Use the bedroom only to sleep (and for sex); not for reading, watching TV or working.
- Turn off the telephone.
- Reduce the brightness of the alarm light.
- If you are awake for more than half an hour, go to another room (with dim lighting) and only go back to the bedroom when you are sleepy again.

3. Food and drinks

- Some people need to stop consumption of caffeinated drinks (coffee, black tea, cola, energy drinks) 4 to 8 hours before going to bed.
- Have a maximum of one or two glasses of alcohol before sleeping; do not have a large meal just before going to bed, do not smoke (nicotine is stimulating), and do not use any sleeping pills (it is important that the biological clock starts working again).

4. Worries and stress

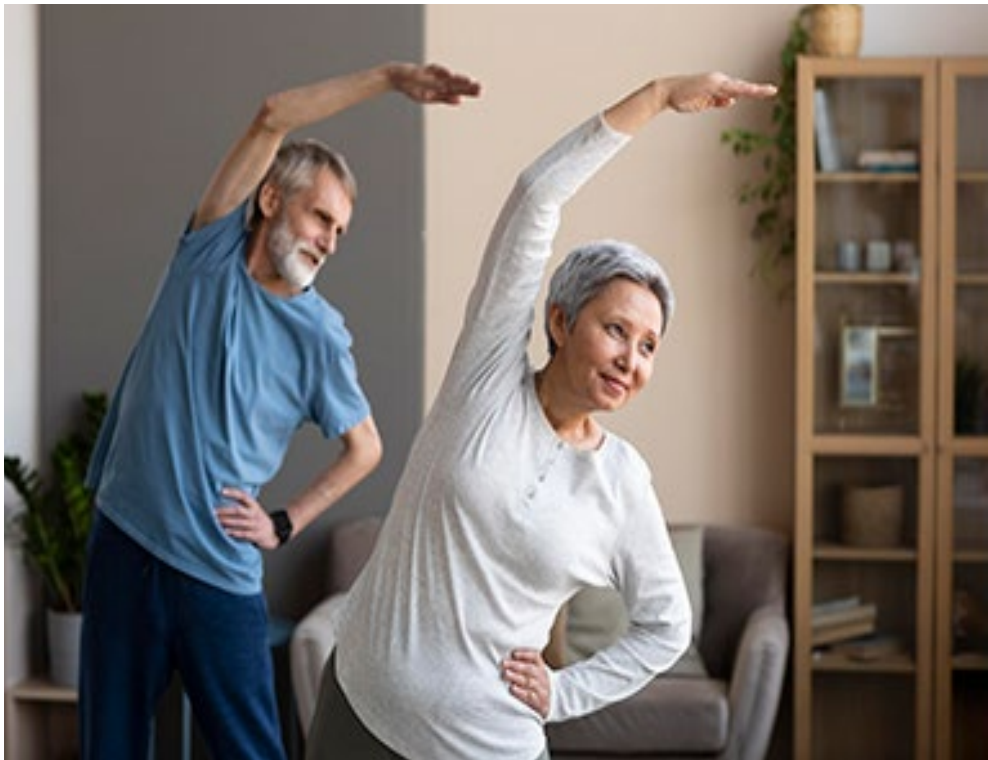
- Make sure the brain is calm: do relaxing activities before bed.
- Do not ruminate when you are in bed.
- If the worrying does not stop, write down the thought that is bothering you and worry about it the next day. If necessary, reserve half an hour for worry during the day or early in the evening.
- If stress keeps you from sleeping, tackle the source of stress (too busy, a bad relationship, concerns about the children, and so on).
- Do relaxing and fun things in life. "Seize the hour" when enjoying a whole day takes too much energy.

4. Physical activity

No matter how contradictory it may sound, exercise helps to reduce fatigue. It also leads to improved functioning, health and mood.

Many people benefit from programs aimed at a gradual build-up of exercise or "low fitness training." These programs build up the level of exercise starting with a level that one can easily handle. Physical therapists offer and guide these programs. Scientific research has shown that exercise therapy reduces chronic fatigue.

Many people manage to exercise more during a few weeks or months, but it is hard maintaining a higher level of physical activity consistently through the years. The tips on the following pages may offer a long-term solution. Not every tip will work for everyone. Use the tips that can personally help you maintain your physical activity at a higher level.



Ten tips that can help to increase your level of physical activity and to keep it up

1. Break the habit

For many people, "not moving" is a deep-rooted habit. It is very difficult to unlearn habits. Nevertheless, try to replace bad habits with good ones. If you always drive to a nearby bakery, then you could, from now on, always go on foot or by bike instead. Be warned that it may take two months to fully unlearn a habit.

2. Make sure you can do the exercise activity

It is important that you can perform the exercise activity that you intend to start. For instance, it is easier to start or continue with an activity like dancing if you have learned how to do it. And if you want to work out in a fitness center, it is useful to know how the devices work. Experts or friends can help. Similarly, if you find it difficult to reach something from a cupboard above your head, then repeat the movement a few times until it becomes easier. Finally, it helps if you don't set the bar too high. If you can cycle 3 km, but not 10 km, then it is better to cycle 3 km; if it doesn't work out with a normal bicycle, then it might be possible with an electric bicycle.

3. Use aids if needed

For some people a counter or watch that tracks the walked or cycled distance motivates to build up physical activity. For others it feels less rewarding; that is personal. To keep moving for the long term, keeping track of distances is usually not enough. For some people other aids may be useful to help maintain physical activity long term: e.g., Nordic walking poles, a rollator, or an electrical bike. For some people it helps to present their physical activity achievements on Facebook, Instagram, or Twitter. The 'Likes' and 'Loves' of friends helps them to stay motivated.

4. Believe in a good outcome

People who expect that exercise will have positive effects on general health and disease activity, maintain exercise activities longer.

5. Choose a physical activity that fulfils personal goals

Choose a physical activity that helps you achieve something that gives you satisfaction. Think carefully about what your goals in life are. You may find it important to go shopping yourself, take the children to school, or go somewhere for a visit. This could mean that cycling or walking is the best physical activity for you, because it helps you to achieve personal goals.

6. Find a physical activity that you enjoy

Some people hate virtually any kind of exercise. Then, nevertheless, try to find an exercise activity that you like a little: ride an electric bike to a terrace nearby and enjoy a drink and the nice weather, walk with your granddaughter to a playground nearby, or dance at home while listening to your favorite music. Choose an activity that you enjoy doing or takes you somewhere that it is nice to be.

7. Stop moving while it is still fun

Do not continue doing any form of physical activity until you have developed a lot of pain or are exhausted. Instead, build it up gradually. If you stop moving while it is still fun, then you will be motivated to move again next time.

8. Find a buddy

For many people it is easier to do a physical activity with other people. If one person in a group applauds or stands up, then others imitate this automatically. Moving together with other people is also more fun because other people can support and encourage you if moving gets tougher. Explore your local community for possibilities to do exercise activities together.

There is a video on the internet of elderly people dancing hip-hop together. They have a lot of fun moving and using hip-hop slang together.

9. Make an action plan

To translate intentions into actions, it helps to make an action plan. Write down when and where you will move and with whom for how long. For example: "Every Monday at 10:30 a.m. I will go out for a walk with a neighbor, every Wednesday at 10 a.m. I will join a gym class and every Friday after breakfast I will bike to the market." These concrete resolutions are better than general intentions such as "I want to move more."

10. Find a nudge

It may take a lot of effort to keep moving. Therefore, it is useful to find a means that helps you move more naturally. A "nudge" may serve this purpose. It is a little push in the right direction that makes you unconsciously do what is right for you, so that it hardly takes any effort. Examples of nudges are piano stairs that make music when you climb them or a dog that comes to you with a dog leash in his mouth because he wants to go out. A few years ago, there was a game on the smartphone where people had to search for Pokémon. The participants in the game covered many kilometers without realizing it. I know someone with a chronic condition who became passionate about photography. To take beautiful nature photos, she sometimes had to walk a long way. Thanks to her photography hobby, she started to move more and more. She still maintains this exercise activity because it gives her a lot of pleasure and therefore requires little effort. If you manage to find something that makes you move instinctively and with pleasure, then this will ensure you keep on moving. Find your own nudge!

5. Emotions and negative thoughts

Emotions

For some people, emotions play a role in the persistence of fatigue. For example, fear of injury can prevent people from moving. Anxiety and worry can also keep them from sleeping. Some people feel gloomy, have little desire to do anything and are less interested in what is happening around them than they were in the past. These can be signs of depression. In the case of anxiety or depression, it is good to seek help from the doctor. He or she can, for example, help with a referral to a psychologist.

Negative thoughts

Some people have predominantly negative thoughts, e.g.: "I am always unlucky; nothing helps against fatigue; whatever I try, it only makes me worse; and I have to (instead of I want to)."

Negative thoughts often arise automatically and it is very difficult to get rid of them. For example, look at the image on page 21. Even if you know exactly how you are being deceived, it is still difficult to look at the photo in another way. Also, when having negative thoughts, you know that it is pointless to think that way, but the thoughts keep looming.

Negative thoughts are also called non-helping thoughts or non-helping cognitions. In cognitive therapy people learn to distinguish non-helping and helping thoughts as well as to change thoughts or accept thoughts. This change in way of thinking is key to changing the course of life.

Often, therapy is not only focused on thoughts, but also on behaviors that help commit to living a life according to one's values and to deal with helplessness, fear, or negative affect. Therapy focused on both thoughts and behavior is called "cognitive behavioral therapy" and it is usually given by psychologists.

If it is not possible to change a problem, behavior or thoughts, new therapies such as Acceptance & Commitment Therapy (ACT) can also be used. The A stands for acceptance, the C for 'commitment to change', and the T for therapy.

Within ACT you learn to let go of unhelpful thoughts instead of changing them or fighting a losing battle against them. You also learn to organize your life better according to what you find important so that life is more satisfying.





Photograph of two tourists in the 'Escher in the palace' museum in The Hague (Craig Chu and Charles Mills gave permission to publish this photograph)

What do you see when you look at the photo?

Your first reaction will be that the man on the left is much larger than the man on the right, but you know this is a deception. The room is actually distorted.

The tiles on the left are smaller than the tiles on the right, the ceiling on the left is lower and the rear wall on the left is closer. Also, the windows in the back are not square or rectangular but are shorter on the left than on the right.

If we look through a hole in the middle of the room, we see a large man on the left and a small man on the right; even though we know they are about the same size. Our brain is so used to looking at square and rectangular rooms that it is hard to see it differently; even if we know it's wrong.

6. Pain

Pain is influenced by all the factors that also influence fatigue. Tackling these factors could alleviate pain. Also, in the case of pain, specific influencing factors differ between people.

However, there is also a difference between pain and fatigue. There is no medication against chronic fatigue, but there are medications available that may help against pain. Your rheumatologist can help you obtain these medications. Also, physical therapy and aids can help against the pain; for instance, a rollator, Nordic walking poles, good footwear, an electric bicycle, or a brace (a device that supports the wrist or knee). Occupational therapists in particular can help advise you about aids. A rheumatologist and general practitioner can help with a good referral.



Effective control of pain helps to sleep and function better, to move more and generally, to feel better. Therefore, a reduction of pain can also reduce fatigue.

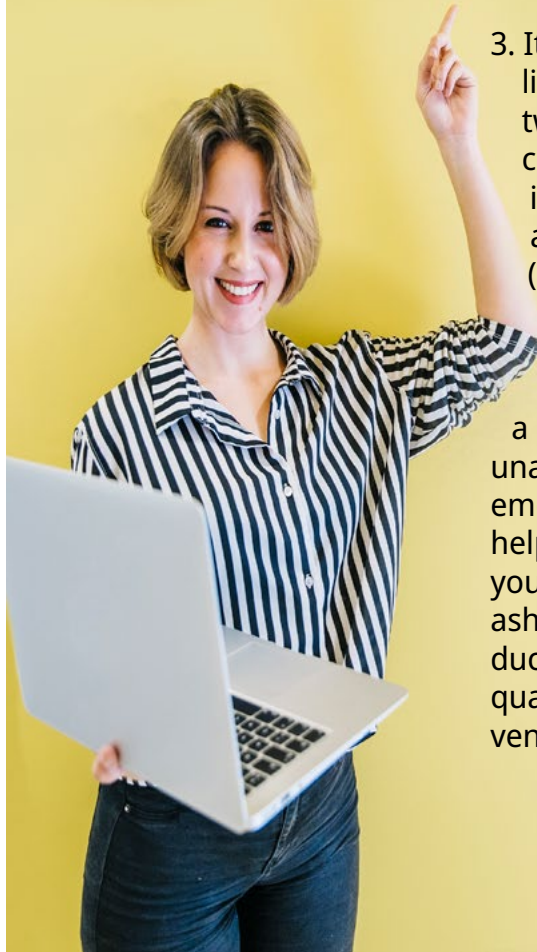
7. Another influence that was not mentioned

You may have indicated that another factor has the most impact on your fatigue. Maybe it's your job, your partner, or lack of acknowledgement by other people. If there is another important influence, it is imperative that you solve this problem.



Conclusion

1. Overweight, disease activity, day-night rhythm and sleep, physical activity, emotions and negative thoughts, pain, and possibly other factors may influence fatigue.
2. Everyone is different and must discover for themselves which factors mainly influence their fatigue. It is important to know that with current knowledge, a healthy lifestyle, including appropriate treatment of the disease, is the best medication against chronic fatigue.



3. It is not easy to change one's lifestyle and it may take up to two months for these changed habits to stick. But it is worth trying. In any case, always make an action plan (see next page).
4. If you are unable to move without help, seek help from a physical therapist. If you are unable to overcome negative emotions and thoughts, seek the help of a psychologist through your doctor. No one should be ashamed to ask for help in reducing fatigue and improving quality of life. Try it! Nothing ventured, nothing gained.

Beyond good intentions: make an action plan!

- 1. Describe accurately what your goal is.**
- 2. Make one or more action plans to achieve this goal.**

The chance that your goal will actually become a reality is much greater if there is an action plan that is as specific as possible. As an example, a goal could be "to increase physical activity." One of the actions to fulfill the goal could be "Walking weekly to the market on Thursday morning and stay there for an hour." The action plan should specify "what" you will do, as well as "where", when and for "how long" you will do this. It is also possible to specify "with whom" you will do this

What?

The action must be specific. If the action is described in vague terms, you cannot work on it because you do not know what to do. "To increase physical activity" is not concrete enough. Then it is still unclear what exactly you are going to do. The action "walking weekly to the market" is concrete.

Where?

It must be clear where you are going to implement the action. The action "Walking to the market" is clearly formulated, because it is clear where you go.

When?

It must be clear when you will carry out the action. This increases the chance that you will actually do it. In this example: "Every week on Thursday morning".

How long?

Also describe as precisely as possible how long you want to carry out the activity. In the example it is during "an hour."

With whom?

If necessary, state with whom you will achieve the goal (e.g., "with my sister"). However, the activity must not depend on someone else.

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This booklet offers tips for targeting chronic fatigue in Sjogren's Syndrome.

First, personal factors that can influence fatigue are mapped. Next, it explains how those factors can be tackled.



Prof. dr. Rinie Geenen is a psychologist at Utrecht University, the Netherlands. He was involved in the development of treatment programs and international guidelines for the treatment of fatigue and pain in rheumatic and musculoskeletal diseases.

***Sjögren Europe is grateful to Prof. Geenen
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Information

<https://sjogreneurope.org>

<https://pubmed.ncbi.nlm.nih.gov>

<https://www.sjogrens.org/blog/13-types-of-sjogrens>



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