

Managing Symptoms of Fatigue in Sjögren's Syndrome

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Introduction

Fatigue is a problem which affects many people with Sjögren's syndrome. Despite it being a common symptom, the effects of fatigue are not easily treated with medication, yet they often have a huge impact on people's ability to fully participate in all aspects of daily life. In this article I will share some of the strategies which can help with the management of fatigue symptoms on a day-to-day basis, and recommend some resources which may be useful for people with Sjögren's who are limited with fatigue.

Fatigue – what is it and how can it affect me?

Fatigue is described as a chronic symptom, when an individual experiences feeling tired, 'used-up' or exhausted, often when it reaches a point where it impacts on their ability to live their life or function properly (Newton, 2012). Fatigue can affect people in a variety of ways. Some people describe mental fatigue, where they may struggle to concentrate or remember things. Other people experience physical fatigue, where their bodies feel very tired or weak, making it difficult to participate in physical activities that are too strenuous or too prolonged. Very often it is a combination of both physical and mental fatigue which affects people's ability to do the things they want to do. Furthermore, pain and stress can make symptoms of fatigue feel worse.

Gaining an overview

First of all, rather than trying to make immediate changes, it may be helpful to have a realistic overview of what you are doing each day for a week or two. It is useful to see if there may be times in the week when you may be doing a lot of high level activity and there is very little time allocated for rest. Then there may be periods when you tend to rest more and struggle to do much activity.



Activity diary

Keeping an activity diary can be a useful way of gaining an impression of the overall picture. It is useful to record what you are doing every hour in the day each day for a couple of weeks using a simple chart. Make a note of whether you are engaged in activity at a high or low level, sleeping, or resting, as in the example below. A high level activity is one which feels as if it will use up your energy reserves more rapidly and may be mental or physical. An activity diary is included in the Fatigue and Arthritis booklet, available free of charge from Arthritis Research UK (Hewlett, Ambler, Fletcher, & Brown). Alternatively, an app available from iTunes, ActiveME (Indigo, 2011) does a similar job. A further example of an activity diary is provided below. The squares on this example all represent an hour in the day. If you wish to divide the squares up in some way to give a more accurate representation of how you spent your time, you can do so.

Activity, Rest and Sleep Diary

	Morning - am											Afternoon - pm												
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

Key:- **H** - High Energy Activity **L** - Low Energy Activity **R** - Rest/ Chill out Time **S** - Sleep

Continued next page

If you are feeling particularly fatigued, an activity which you may ordinarily regard as low level may feel high. You can just record how it felt for you on that particular day. When you are recording rests, bear in mind that rest is an absence of activity. Many people feel that they are resting while watching television or listening to music or an audiobook. If this is truly a “switch off” time for you, it would be fine to record these times as rest. However, if you are watching something which stirs up emotions or requires intense concentration, it may be more realistic to record it as low or even high level activity.

Remember to record when you sleep. However, there is no need to keep an eye on the clock during the night if you are awake. A rough estimate of the number of times you awoke and duration of wakefulness in the night will be sufficient.

Narrowing it down one step at a time

When you have an overview of one or two weeks of activity plotted on a chart, it is easier to work out where the difficulties may lie, or what could be tackled first. You can ascertain whether you are having any rest breaks, and how frequently. Additionally, you can work out whether you have a balance between rest and activity. If you find that you are doing a lot at the beginning of the week and using the weekend to recover in order to start again on Monday morning, it is likely that you are engaged in a “boom and bust” pattern. If this pattern can be broken, you will probably feel some benefit and negate the need to use up valuable energy in recovering from the times when you may otherwise have “crashed”. On occasions, in order to avoid feeling too fatigued, some people avoid certain activities which they feel will deplete them of energy. However, completely avoiding activities may result in your capacity to carry out certain tasks being reduced as you become deconditioned. In either scenario, the visual representation that a completed activity chart gives can be a useful starting point.

When reviewing the completed activity diary, you may find that you have been doing too much. In this case, it is worth reducing your activity levels in some way. Useful questions to ask yourself are: “Do I always have to do this?” “Can someone else do it?” “Is there an easier way to complete this task?” If the answer to any of these questions is “yes”, then this is a starting point to reducing your activity to a more comfortable level.

Secondly, you may find that you need or want to do everything that you are doing, but are getting minimal time to rest in between activities. In this case, you can perhaps plan for your next week by purposefully spreading the activities out over the week and timetabling in planned rests.

If your activity levels are minimal, you could start to set some goals, by planning what you would like to do. Perhaps planning to do a small amount over the next couple of weeks could be a useful starting point and as you gain more confidence, your activity levels can be gradually graded up over time.

Pacing and rest

Pacing yourself is a way of completing tasks with minimal discomfort. Spreading out an activity into smaller blocks of time with rest periods and other tasks in between can increase your efficiency; it can also help to avoid using up energy recovering from an increase in fatigue symptoms. An example may be cleaning the house. This is not an activity which needs to be done all in one go. It can be spread out over the day or the week. Some people find that cleaning one room a day works well for them rather than working from start to finish to “get it done in one go”. In order to change the way you do things, you will need to establish new habits, or ways of doing things.

Relaxation

Regular relaxation can help, particularly if you find it hard to switch off and rest or if you regularly feel stressed. There are many different types of relaxation sound tracks which can be purchased on a cd or downloaded from the internet, including progressive muscle relaxation and guided imagery. Relaxation can be particularly useful when starting to pace, especially if you find it hard to stop and rest. Try doing a short relaxation track daily. It takes time to become good at relaxing and you should start to find that it becomes easier with practice. Mindfulness is another approach which has recently gained interest from the media as well as from health care practitioners. Mindfulness techniques allow us to focus on the present and redirect our attention from things that have happened, or may happen in the future. It is a technique which encourages relaxation and acceptance. A self-help guide, together with an audio cd, is available from booksellers (Williams, 2011).

Setting a baseline

A baseline is the minimal amount of activity that you can do without causing a flare-up of fatigue symptoms. Your baseline level of activity on a bad day when you are particularly tired may seem difficult, yet should still be achievable. On a good day, it will probably seem easily attainable. You may not know what your baseline level of activity is. In order to find it, it may be helpful to reduce your current activity level slightly until it feels that your activity level is consistently achievable.

Sleep

It is natural to feel fatigued if you are having difficulty with sleep. If pain is keeping you awake at night, it is worth speaking to your doctor. You may have difficulty falling asleep, or wake frequently in the night. Good sleep hygiene can help promote sleep. Simple lifestyle changes can make a difference. The body should associate bed with sleep. Removing entertainment and work from the bedroom including television, laptops, computer tablets, smartphones and work can help the brain switch off from the busyness of the day. Removing clutter allows the bedroom to feel it is a peaceful place to be. In the evening it is a good idea to start a ‘wind down’ for bed, two or three hours before you are ready to retire. This may involve avoiding any television programmes which are too stimulating or upsetting, and perhaps taking a warm bath and having a warm milky drink or chamomile tea. Ensure that you are ready for the following day prior to winding down. You may wish to jot down any reminders or have bags and items ready for the next morning.

If you do suffer with excessive daytime sleepiness, it is always worth ensuring that you do not have a primary sleep disorder by having a discussion with your general practitioner.

Goal Setting

Once you are pacing yourself well, have addressed any sleep issues and are working at a baseline level of activity, you may find that you still become fatigued, but hopefully it is now not as debilitating or unmanageable. You may feel ready to increase an activity you are already doing, or choose a new goal to work towards. It is important to try and make sure that you have a balance between tasks you have to do such as work and housework, and other pleasurable pastimes such as leisure and social activities. A healthy balance can improve overall quality of life. It is worth reflecting on whether there may be some areas in your life which have not had so much attention; perhaps you regularly prioritise certain activities over others. Hobbies and leisure activities are often neglected if work, caring for others and housework have become the main priorities. If you wish to choose a new goal or increase something that you are already doing, SMART goals (specific, measurable, achievable, realistic and time-limited) are useful as you can determine how much

Continued next page

of an activity you would like to achieve by when. To make a goal SMART, ensure that you pick an activity not an idea (e.g. 'walking', not 'fitter'), decide how much you want to do, (such as '20 minutes', not 'more') and decide when you want to do this by (tomorrow is unlikely!).

Grading activity

When you have chosen a goal or have decided to increase something that you are already doing, you can start to gradually build on the levels you are currently managing. Graded activity or exercise is a way of increasing your capacity to do a certain task. This is done by adding small amounts to what you are currently doing. It is a slow process and it is important not to make large changes too quickly to minimise a potential flare-up of fatigue symptoms. A usual rule of thumb is to choose an activity that you can manage comfortably (or have achieved a baseline for) and to increase the baseline level by 10-20%. You can either choose to increase the time you spend on the activity, or if appropriate, to increase the effort that you put into it. For example if you are comfortably managing to walk for 10 minutes, you could increase this to an 11 or 12 minute walk, or walk at a slightly brisker pace for 10 minutes. It is important to maintain the new activity level for a period of time. At first it may feel more challenging as you are pushing your body beyond a comfortable boundary. However, the new level should then become your new baseline. Once you have maintained this comfortably for a period of time, you may decide that you want to stay at the new level or increase it again by another 10-20%.

Conclusion

The above material is intended as a guide. Everyone's situation is different and if you are struggling with applying any of the advice, it would always be advisable to seek support from your health care practitioner. Fatigue management in long-term conditions has really only become topical in recent years. Following on from this, fatigue symptoms experienced by people with Sjögren's have gained more coverage in the academic literature. However the clinical resources are not always available to help Sjögren's patients with fatigue management. It is my hope that in the near future, the situation will change. The above suggestions have been based on advice which is routinely given to patients attending chronic fatigue syndrome clinics, the advice being equally valid in the management of any condition where persistent fatigue is a problem.

References

- Hewlett, S., Ambler, N., Fletcher, D., & Brown, S. Fatigue and Arthritis. In A. R. UK (Ed.). Chesterfield: Arthritis Research UK. Available from: <http://www.arthritisresearchuk.org/arthritis-information/arthritis-and-daily-life/fatigue.aspx>
- Indigo Multimedia. (2011). ActiveME: Apple iTunes.
- Newton, J. L. (2012). Managing fatigue in the syncope unit. *Europace*, 14(12), 1696-1699.
- Williams, M. (2011). *Mindfulness: A practical way of finding peace in a frantic world*. Great Britain: Piatkus.