



#### **Disclaimer**

We have made every effort to ensure that the information in this publication is correct. We do not accept liability for errors or omissions. The law and government regulations may change. Be sure to seek local advice.

The information should not be relied on to suggest a course of treatment for a particular individual, and it should not be used in place of a visit, call, consultation or the advice of a physician or other qualified healthcare provider.

#### **Contributors**

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### An adapted resource

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**La Fondation ARSEP (France)** Fatigue et sclérose en plaques, 2017 **MS Australia** MS and Fatigue, 2018 MS Society (UK)
Fatigue booklet, 2016

### **Contents**

What is MS fatigue?	4
What causes MS fatigue?	6
How is MS fatigue different to ordinary fatigue?	8
How to describe MS fatigue to others	10
Understanding and managing MS fatigue	12
Lifestyle changes	17
Drugs for MS fatigue	28
Further resources	30
Sample fatigue diary	32
Fatigue diary	35

#MyInvisibleMS

Version 1: 2020

The graphics in this resource were adapted from the 2019 World MS Day campaign, 'My Invisible MS'.

# What is MS fatigue?

Fatigue is one of the most common, troubling symptoms experienced by people with MS. For some people, it is the symptom that affects them most.

MS fatigue is not only difficult to define but it is an invisible symptom (in other words, others can't see it). This can make it difficult to understand or explain to others who may interpret it in the wrong way. It is often described as heavy tiredness (lassitude), general weakness or lack of energy but for some it may be described as total exhaustion. The reality is that every definition is correct because the experience is subjective and everyone experiences MS fatigue differently.

Unlike ordinary fatigue, MS fatigue can occur suddenly, usually without reason, lasting longer and taking longer to recover from. It can be temporary such

as during a relapse (known as 'short circuiting'), an infection or unrelated illness, or when starting some MS medications. Alternatively, it can be ongoing (chronic), even after rest.

MS fatigue can temporarily worsen other MS symptoms (such as muscle weakness or vision issues), but for some people this can reduce again after rest. MS fatigue can also result from the effect of other MS symptoms such as mobility (walking) problems, pain, muscle weakness or depression.

Sometimes people experience cognitive fatigue, which affects memory, learning, concentration, making decisions and attention span (also known as 'brain fog').

Some people experience chronic MS fatigue, which means it is frequently present, even when resting. It often increases in the second part of the day and can be made worse by stress or heat.



"Fatigue is the most invisible of MS symptoms! It's also the symptom that's the most difficult for friends, family and care givers to understand. Fatigue is the one symptom that makes people probably think that you are making a fuss about nothing at all."

Tara is from India



# What causes MS fatigue?

The causes of MS fatigue are not yet well understood. It is thought to result from a range of different factors, partly caused by MS itself (known as primary fatigue) and partly by other factors (secondary fatigue).

Primary MS fatigue is due to changes in the brain and damage to the central nervous system. The damage affects the nerves by interrupting messages from the brain and spinal cord to the rest of the body. As a result, your body has to work harder to function, which can lead to a build-up of MS fatigue. Muscle weakness and cognitive demands are also affected by the changes in the brain, so they too use more energy, which can lead to MS fatigue.

Secondary MS fatigue occurs from the effects of living with MS. For instance, MS symptoms such as depression, pain or sleep disturbance from spasms or incontinence can all make MS fatigue worse. MS fatigue may also occur as a side effect of some medications or from inactivity, stress, poor diet or an infection. Other medical conditions can also cause or worsen MS fatigue.



"Fatigue in multiple sclerosis is something quite special because, we can sleep as much as we want, it doesn't change anything. It's really like a crushing exhaustion. You can be fine and in a few minutes you feel exhausted, and everything gets too hard.





Moving, eating, working, talking... everything becomes very hard! It's like your body falls asleep for you, but your head doesn't fall asleep. Sometimes even sleeping is also too difficult, because your body has gone out but not your head."

**Marie** from France has been living with MS since 2016

# How is MS fatigue different to ordinary fatigue?

MS fatigue is more than the tiredness that everybody feels after exertion or missing a good night's sleep. This type of tiredness can still affect you, but MS fatigue goes beyond that.

MS fatigue can be physical and mental; it saps energy in an instant and can stop you from completing tasks. MS fatigue can be very debilitating and, unlike 'ordinary' fatigue, it can take a long time to recover from.

MS fatigue is often overwhelming. It can happen at any time without warning or without any apparent reason. Some people say they experience MS fatigue after gentle activities such as writing or reading and they immediately need to rest. Others say that MS fatigue happens after physical exertion, such as taking the dog for a walk or doing the shopping. For others, MS fatigue can happen after cognitive exertion such as working on the computer and completing mentally-demanding tasks. You may also experience MS fatigue when you wake up, in some cases every day, even after a good night's sleep.

"My MS fatigue is like an extreme jet lag. Even after a good night's sleep, I get up in the morning as if I spent the night outside."

**Najia** from Morocco was diagnosed with MS in 2014 but had been living with MS symptoms for many years before this





#### Here are some common observations about MS fatigue:



- Tends to worsen as the day progresses
- Appears more easily and suddenly than 'ordinary' fatigue
- Is generally more severe than 'ordinary' fatigue
- Tends to be aggravated by heat and humidity
- Is more likely to interfere with daily activities than 'ordinary' fatigue

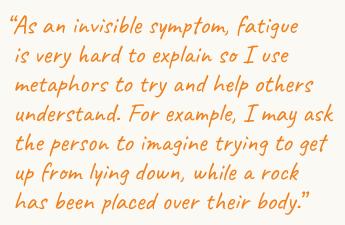


# How to describe MS fatigue to others

It can be complicated to describe your MS fatigue to friends, family, colleagues and healthcare professionals, but helping others to understand can make your daily life with MS fatigue less frustrating.

Sometimes friends and family may notice the effects of MS fatigue. For example, a relative might notice that you are walking more slowly later in the day, or they may notice that after completing certain tasks you become much slower in responding to conversations. Seeing the effects of MS fatigue can help those around you to offer assistance and support.

There will be times when your MS fatigue is not obvious to others, because it is an 'invisible' symptom. Using analogies or metaphors to describe MS fatigue can help friends, family and colleagues understand and relate to what you are experiencing.



**Laura** from Kenya was diagnosed with MS in 2006. In 2019, she was diagnosed with NMO (Neuromyelitis optica)

You may find these examples useful to describe your MS fatigue:

#### The traffic light explanation:

You feel like a car that passes a green light and can continue on its journey as it has enough energy. The car needs to think about stopping to avoid the risk of an accident. Red
 The car needs to stop and rest to be able to continue.



#### The battery explanation:



The battery is fully charged, it is functioning normally and has all the energy it needs to complete day-to-day activities.



The battery is running low, it is slowing down so you need to limit its use and plan a recharging period.



The battery is completely out of charge so all activities come to a halt. The recharge time will take longer if a recharge didn't happen as and when necessary.

"My fatigue usually gets worse with heat and stress situations. It also usually gets worse throughout the day as if my personal battery is emptying."

José María Ramos from Spain was diagnosed with MS in 1999

# Understanding and managing MS fatigue

It is possible to manage, or even reduce, MS fatigue effectively, to be able to maintain a healthy and active lifestyle.

Managing MS fatigue involves maximizing and using energy efficiently, as well as prioritizing tasks. Taking time to analyze your MS fatigue and to find strategies to manage it can be a tiring exercise in itself. However, it can be really useful to identify things that bring on your MS fatigue, and find ways to work around triggers.

There is no one-size-fits-all answer to managing MS fatigue: everyone is different, so the way you manage your MS fatigue probably won't be exactly the same as someone else's. However, this section will help you to consider and deal with the things that make MS fatigue worse, and provide a few suggestions for managing MS fatigue.





# Using a fatigue diary

Keeping a fatigue diary can help you to understand the ways you experience MS fatigue (refer to the diary in 'further resources' on page 30). By looking at your fatigue diary alongside your general health and any medications you are taking, you and your healthcare team might be able to see certain things that seem to make your MS fatigue worse. By finding patterns in your experience of MS fatigue, solutions can then be discussed and put into place.

By completing another MS fatigue diary after you have made changes or had underlying symptoms treated, you can compare the two and see if the changes you have made have had the desired effect.

Many people don't like using diaries but it can be very helpful. People who use a diary often report a positive change in their MS fatigue, and also an improvement in their

families' understanding of the effects of MS fatigue and therefore the support they can offer.

When describing your activities, you might find it useful to include details of how they are undertaken. For example, shopping could be a short trip to a small local shop or it could involve lots of walking around a large supermarket, pushing a heavy trolley. The more detail you include, the more useful your diary will be.

How and when you use a fatigue diary is a personal preference. Some people will try to make notes as they go, and others will write at intervals throughout the day.

If you are filling in the diary at the end of the day, just be aware of how your current MS fatigue levels might affect how well you remember how you

were feeling earlier.



Lack of sleep might be the main cause of your MS fatigue, or one of several causes. There are any number of things that might disturb sleep:

- muscle spasms or restless legs
- pain
- needing the toilet
- insomnia
- too much caffeine or alcohol, particularly if it's close to bedtime
- noise
- temperature
- anxiety
- depression
- light
- medications

Completing a sleep diary (or including sleep in the fatigue diary mentioned above) can help identify triggers and strategies that you and your healthcare team can put in place. For example, it may be useful to follow a sleep hygiene programme, or look at medication to help with spasms, depression or the need to go to the toilet so often.



Infections like the common cold or bladder infections often lead to unexpected tiredness, particularly if they raise your body temperature. If you have an infection it is important to get it treated quickly, to rest, drink plenty of fluids and keep your temperature down.



#### Impact of medications on MS fatigue

Many drugs commonly used to manage MS and related symptoms have side effects that can add to MS fatigue. If it's a new medication, or you are changing doses or changing the time of day you take the drug, your MS fatigue levels may also change.

If you think your medication is having an effect on your levels of MS fatigue then speak to your doctor. They will be able to look at all the medications you are taking (including over the counter drugs) and make changes to see if you experience a positive (or negative) change in your MS fatigue levels. Sometimes this can be trial and error but many people find it helpful. Remember, you should not adjust your drugs without advice from your healthcare team.





Anxiety, depression and mood changes are not uncommon in MS, and they can cause feelings of fatigue. Equally, MS fatigue can also have an effect on mood. It can be difficult to untangle the two issues – they might be affecting each other.

There are many options for treating these emotional symptoms. Successful treatment might help lessen MS fatigue and, in turn, finding ways to minimise MS fatigue can help relieve stress and anxiety.

Mindfulness can be very helpful in managing emotional symptoms and many people with MS report it has a positive impact on their MS fatigue. Find out more about mindfulness techniques by following the links in the further resources section, at the end of this booklet.

If the emotional symptoms are very intense, speak to a member of your healthcare team, such as an MS nurse or psychologist. They may give you medication or refer you to a counsellor to help manage the emotional difficulties you might be experiencing.



MS can cause a wide variety of symptoms, but it's important to remember that not every health issue is necessarily related to MS. Other possible causes, such as menopause, anaemia and thyroid issues might also be considered. All of these can cause MS fatigue, or make it worse. Seek advice from your healthcare team if you are unsure or experience symptoms that appear unrelated to your MS.

# Lifestyle changes

To manage MS fatigue, it can be helpful to look at your lifestyle – how we, and those around, approach work, rest and leisure time. The idea is to make tasks easier and make best use of the energy you have.



Take some time to think realistically about how MS fatigue affects you. Consider what adjustments you and others feel able to make. Try to find a balance of activity and relaxation, exercise and rest, work and social life. Remember that some of the changes you make could involve family, friends or work colleagues.

"My family understands my fatigue as what pushes me to my limit. It is not so easy at work though, as there isn't always the same empathy among colleagues."

And from Uruguay has been living with MS since 1996

Mobility devices can be a useful way of conserving energy. Even if you don't use a device every day, when your fatigue levels are particularly high, you may find it helpful to have the option of using a walking cane, walker or chair. This can help you to reduce the amount of energy needed when moving around.





**Kostas** from Greece was diagnosed with MS in 1991

"The only practical thing I've tried that works is to plan my activities. I try to avoid activities that take up too much energy or time but I don't deprive

myself! I write everything in my agenda where I make time for myself during the week without activities so I can take a rest if I need to."

**Daphne** from Belgium was diagnosed with MS in 2014



#### **Prioritizing**

Making changes to your routine can be hard, but prioritising activities can mean saving energy for the things you really want or need to do. If MS fatigue means that not everything can get done in a day, then concentrating on the most important tasks can help. One way you might do this is to list all the activities you do in a typical day or week:

- Mark which are important to you
- Mark those jobs you would rather not do
- Mark those jobs that can be done less often
- Mark any that don't really need doing at all

Look at the activities you have said are important and think:

- Can they be done in a more energy-efficient way?
- Could they happen at a different time when it would be easier?
- Can you get help for any of these tasks?
- Can these tasks be divided over the day or week?



#### **Planning**

By using the suggested strategy in the 'prioritising' section, you will know your priorities and this can help you to plan your time more effectively. The idea of making a timetable for a day or week may seem a little strange or regimented at first, but planning ahead can help you be more confident of getting things done.

Planning ahead can mean, for example, building in 'down time' to recuperate if your MS fatigue makes you tired at a similar time each day. If you have a particularly tiring task ahead, a plan lets you make space for rest before, after or both.

Some simple tips can make planning easier:

- Set yourself targets, but keep them realistic
- Try to balance your day between easier and more difficult tasks, making time to rest
- Split a large or heavy task into bite size stages, to be done a bit at a time. For example, if you're cooking a large meal, perhaps find recipes where you can pre-prepare parts of the dish, allowing for breaks in-between. Alternatively, you might want to 'bulk bake', by preparing a number of dishes in one go that can be eaten over a few days. Or, if you're

driving somewhere, plan to take a break along the route. Consider walking the dog along a public transport route where you might find a seat at the station, or be able to catch a bus or train back

Share your plans with others, especially your family and friends and, if possible, your work colleagues. This may improve their understanding of how MS is affecting you and enable them to support and assist.



People might say to you, 'If there's anything you need...' or 'If there's anything I can do...', but it is not always easy to ask for help, even when it is offered.

It can be useful to prepare a list of tasks that you would like help with. You might have done this already when making a list of priorities (see the 'Prioritising' section). That way, if someone does offer to help, you can easily tell them how they could support you.

When asking for help, here are some tips that you might find useful:



Asking for help is a sign of strength, organisation and a desire to get on with things. It's not a sign of weakness.

#### Break down the task

Most jobs are made up of smaller individual tasks. Getting help with one thing might mean the task is more manageable.

#### **■ Timing**

Work out how long you think a task will take and when it needs to be done by. Don't forget to add in time for breaks!

#### Categorize

It may help to categorize tasks into 'personal', 'household', or 'healthcare'. You may not feel comfortable asking some people to do certain kinds of tasks.

Don't forget to ask for help from health and social care professionals as they might also be helpful when looking at how you approach daily activities.



It almost goes against common sense to exert yourself if you experience MS fatigue, and MS symptoms can make exercise difficult. However, exercise helps to keep your body working at its best. Exercise can improve



strength, fitness and mood and stop muscles from losing strength over time (deconditioning). Deconditioning can be painful and make mobility or weakness problems worse. Lifting mood, building strength and avoiding deconditioning can all help with managing MS fatigue.

It is possible to do too much exercise though. Exercise needs to be balanced with rest. You may also want to avoid exercising too close to bedtime. You may want to do activities in a group or you could carry out exercises at home on your own. In some of the resources at the end of this guide, you'll find examples of exercises you can do at home. If you have access to a physiotherapist, they can also work with you to create an exercise programme.

If heat makes your MS fatigue worse you might want to plan your exercise to avoid long sessions which can lead to overheating. Alternatively, some people find water-based exercise helps maintain a steady temperature. Cooling wristbands may also help.



# Managing MS fatigue at work

You might need to ask your employer to make some changes, such as more flexible hours, regular rest breaks, arranging a parking space closer to the entrance, or looking at your work environment to make sure it is accessible for you. As mentioned in the 'organising living and work spaces' section, an occupational therapist may be able to

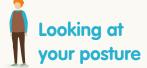
help, so asking your employer to enable them to come into your workplace could be a positive step for you.

You don't have to tell your employer that you have MS, but if you do decide to, this can help your employer understand MS and, in turn, give you better support. Follow the links in the further resources section to find out more about telling your employer about your MS.

"On a professional, social and family level, I especially notice fatigue, because I try to fight against the problem and not live with it. Fatigue especially affects my daily life — I want to keep competing as an athlete so I push myself but can't always."

**João** was diagnosed with MS when he was 34. He particularly notices fatigue in his daily life due to his profession as a cardio-fitness instructor and bodybuilder.





You could save energy on a lot of everyday tasks by making sure you have a good, relaxed posture. The basic idea is to:

- have an upright and symmetrical posture
- avoid too much twisting and bending

Keeping a good posture takes practice, but with time it can become easier, as your body re-aligns itself.



For some people, rest helps relieve MS fatigue and can be an important part of managing it.





Resting can prevent you getting to the point of complete exhaustion and coming to a sudden halt, half-way through a task. Planned rest can give you more control over when you choose to be active and when you take a break.

Some people prefer a few small breaks, or you might feel better after just one longer rest at a particular time. For example:

- Try taking a few short rests or 'power naps', through the day
- Try taking one longer rest, at the same time each day
- Take a break between coming home from work and getting ready for an evening out

When you rest, try to make your rest as complete as possible. Doing smaller jobs around the house, talking to the family or watching TV might be more

relaxing than work or chores, but it is not really resting. It can be tricky, but the aim should be to switch off both the mind and the body. You might want to have a short sleep, meditate or use relaxing music to help clear your mind.

If you find that worries disturb the time you have set aside for rest, try writing down these concerns and 'shelving' them while you're resting. You might find it easier to tackle them once your energy levels are back up again. If resting helps you manage your MS fatigue, it is important that people around you realise how valuable this quiet, undisturbed time is.

You may want to consider complementary therapies to help you relax, such as massage, yoga, t'ai chi, aromatherapy or meditation. Find out more about yoga and complementary therapies by following the links in the further resources section, at the end of this booklet.



Combining sensible exercise with a balanced diet can also help you maintain a healthy weight and get the energy you need. Weight loss and weight gain can both be issues for people with MS and can make coping with MS fatigue more difficult.

What you eat can also make a difference. For example, large, hot meals can make MS fatigue worse and caffeine or sugary snacks might have an initial 'pick-me-up' effect, but may leave you feeling more tired later.

Some people with bladder problems drink less to reduce their need to go to the toilet. Not drinking enough water, however, can lead to dehydration which can cause MS fatigue. You may want to avoid drinking lots too close to bedtime.



# Organising living and work spaces

Sometimes the simplest changes can make your home or workplace more 'energy efficient'. Useful changes to your environment, such as those mentioned here, don't always have to involve specialist equipment or major alterations:

- Keep items that you use regularly within easy reach to avoid frequently getting up and down.
- Items that are used together can be stored together – in the kitchen, for example, you might want to keep the kettle, tea and mugs together in one place.
- Store lightweight items that are rarely used in higher spaces and store heavy items that you use less often at a lower level.

- Keep work areas as uncluttered as possible.
- Make sure the lighting is good, to avoid eye strain as this can increase MS fatigue.
- Consider the items you use, like pens or cutlery. Would they be easier to use if they were lighter, had larger handles, or were adapted in some way?
- Some tasks, like preparing vegetables or ironing, can be done sitting down instead of standing
- Ask for help from your healthcare team. They may be able to refer you to an occupational therapist who can help you assess the spaces and equipment you use, at work and at home and may suggest adaptations or equipment that could help.

# **Drugs for MS fatigue?**

Although there are currently no drugs licensed specifically for MS fatigue, certain drugs licensed for other conditions are sometimes prescribed.

There is limited evidence for their effectiveness, and what evidence there is suggests they are less effective than the MS fatigue management tools discussed previously. However, some people find that drug treatments help them manage their MS fatigue.

Amantadine
(sold under several brand
names including Symmetrel, Lysovir,
Osmolex, Gocovri, Amantrel,
Comantrel, Neaman, Symadine
and Viregyt-K)

This drug is licensed by the Food and Drug Administration (FDA) and the European Medicines Agency (EMA) to treat Parkinson's disease, as well as some viral infections. Unfortunately, research regarding its use in treating MS fatigue is not conclusive. Some guidelines for MS (such as the UK National Institute for Health and Care Excellence guidelines) state that a small benefit might be gained from taking a dose of 200mg daily. Side effects can include insomnia and vivid dreams.

Modafinil
(sold under brand names
including Provigil, Alertec, Modavigil
and Modalert)

This drug is used to treat narcolepsy, a sleep disorder which causes people to sleep excessively during the day. There have been several small studies looking at modafinil in the treatment of MS fatigue, but they have shown no or limited results<sup>1</sup>. However, a recent meta-analysis showed that

modafinil may have some benefit <sup>2</sup>. There is, though, the potential for addiction and as a result, many specialists are not willing to prescribe it for MS fatigue. Side effects can include insomnia and headaches.

- 1 https://www.ncbi.nlm.nih.gov/pubmed/26654280 https://www.ncbi.nlm.nih.gov/pubmed/24321164 https://www.ncbi.nlm.nih.gov/pubmed/21561959 https://www.ncbi.nlm.nih.gov/pubmed/15824337
- 2 Multiple Sclerosis Related Disorders. January 2018;19:85-89 https://www.ncbi.nlm.nih.gov/pubmed/29175676



## **Further resources**

For more information and support, you can contact your nearest MS organisation. If you're not already in contact with them, use the 'find support near you' tool on MSIF's website to see where your closest MS organisation is:



#### **Useful links**

#### **Mindfulness**

https://www.mssociety.org.uk/careand-support/everyday-living/ mindfulness-and-ms

#### Talking to your employer about your MS

https://mssociety.ca/managing-ms/ newly-diagnosed/talking-about-ms/ employers

#### **Exercises and yoga**

https://www.mssociety.org.uk/care-andsupport/everyday-living/staying-active/ simple-exercises-for-ms

https://www.msaustralia.org.au/wellbeing-ms/exercise-activity

Multiple Sclerosis Society of India – www.youtu.be/Akw5uXzFV5A

Italian MS Society – www.youtu.be/ J4HzxW284P4

www.mssociety.org.uk/care-andsupport/ everyday-living/staying-active/yoga-for-ms

https://www.nationalmssociety.org/ Living-Well-With-MS/Diet-Exercise-Healthy-Behaviors/Exercise/Yoga

http://emforma.esclerosismultiple.com/

#### **Complementary therapies**

https://www.msif.org/wp-content/ uploads/2014/09/MS-in-focus-15-Complementary-and-alternativetherapies-English.pdf

https://www.mssociety.org.uk/ about-ms/treatments-and-therapies/ complementary-and-alternative-therapies

# Sample fatigue diary

Some people find it useful to keep a fatigue diary. By keeping a note of your MS fatigue levels at different times of the day and during different activities, you may begin to see patterns.

It's important to complete the diary on 'good' days as well as 'bad' days. Over time, this can highlight particular factors that may be causing MS fatigue, making it better or worse. Once you've identified this, you can

use the diary to think about and discuss ways to manage these factors.

Read more about using a fatigue diary on page 13.



Date: 10 July

Describe last night's sleep: Worse than normal. The temperature was quite hot which made it hard to get to sleep and I woke up a few times in the night. Felt more tired than usual when I woke up.

Time	Description of your activities	Fatigue score*	Comments
07:15	Wake up, shower and brush teeth.	5	Slight numbness in my left arm.



Time	Description of your activities	Fatigue score*	Comments
09:30	Get bus to super- market for weekly shop.	6	
09:45 - 11:15	Walk around supermarket, pushing trolley. Pack bags and load into car.	8	Balance gets worse - slows me down.
12:00	Get bus home and unpack bags.	10	Exhausted.
13:30	Sit down and rest.	8	Takes a long time to recover.
15:00	After lunch, respond to emails on computer and have a work call.	6	Difficult to concentrate.

\* 1 = low to high fatigue = 10

#### Description of your activities Fatigue score Time 17:30 Partner arrives Right arm feels home with children tired and makes dinner. 18:30 Sit down to eat with family. Play with younger Feel unsteady on my 19:00 son. 19:30 Sit down while partner takes children to get ready for bed. 22:30 Get ready for bed. Still a bit 'fuzzyheaded'. Arms and legs feel heavy. \* 1 = low to high fatigue = 10

# Blank fatigue diary template

Either you can use the template below or you can download the template at <a href="https://www.msif.org/fatigue">www.msif.org/fatigue</a>

Describe last night's sleep:			
CSCIID	e iusi iligili s sieep:		
Time	Description of your activities	Fatigue score*	Comments
		rungoo ocoro	

FATIGUE: AN INVISIBLE SYMPTOM OF M

Гime	Description of your activities	Fatigue score*	Comments

Time	Description of your activities	Fatigue score*	Comments
			* 1 = low to high fatigue = 10































































































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- www.youtube.com/user/MSIFmedia