



## **Pacing**

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Pacing is a tool which you can use to help reduce the overwhelming levels of fatigue that can accompany people recovering from Encephalitis and the subsequent brain injury.

In the early days you may want and need significant periods of sleep. This is a good time for the body to heal. Eventually you may feel that the fatigue you experience is impairing your quality of life. This is where pacing may have a role to play.

Pacing does not happen naturally. It is a technique which you have to learn with patience, gradually and apply to all aspects of your life, even if it changes your life style. It brings discipline and routine into your life. It may sound boring but your recovery may depend of how well you plan and organise your daily life.

The mechanism is very simple: you do not need to rush to do everything in one day until you get exhausted and then just rest for few days, because overdoing things on a good day makes you so tired that you need more than one day to recover. If you do less than you think you can and have plenty of rest on a good day you will not be overly fatigued on the next days. Moreover you will be able to do the same level of activity combined with the same level of rest the following days.

Activity, break, activity, break is your new routine that helps you going through recovery.

What happens in practice is a bit more complicated as the natural tendency is to push yourself to finish your job and to have a rest afterwards. Also it is hard to know and accept your new strengths and limitations.

### **Why do you need pacing?**

After the acute phase of the Encephalitis, you begin the recovery process, when you may discover that your life is turned upside down and your body does not respond to things the way it used to. Your life is divided between good days and bad days. On bad days you feel pessimistic, lack strength or the will to do anything. On good days you feel full of energy and try to do everything making up for the loss on the bad days. The result does not make you happy because you overdo things on good days, making you feeling even worse on the bad days. The tiredness you feel is greater than usual and it takes you more time to recover than before, shortening the number of good days. You start to ask yourself if you will ever be able to return to the way you used to be. Your daily life becomes a challenge for you, your family and friends.

### **How does pacing work?**

The success of pacing is to stop your activity before you feel the need of a break; stop before you feel too tired to do anything, even to rest. Don't wait until you complete your activity if this activity is too much for you. Have a break and then start again. Follow this rule everyday with every single activity, regardless of where you are: work, home, travelling or driving. Think of your capabilities and limitations, plan everything you do ahead and follow your plan. Be confident but also realistic about your strength and capacity.

Imagine that you are running the 10k, but you can only run 5k without struggling. After that it is a life and death fight to finish and you won't get to reach the finishing line. You will collapse at the 9k. But if you stop at 5 k and have a break, building on your energy, you will be able to continue the race and reach the finishing line without collapsing. You will be smiling and looking forward to the next race. The reason is pacing your activity; dividing the race into 2 stages and building on your energy during your break.

Pacing does not allow you to get exhausted and the fatigue to accumulate. You will not need more and more breaks and your good days will prevail. You need to start thinking of what you can do rather than what you cannot do. This makes you more confident that your recovery will continue upwards instead of downwards.

### What does activity mean?

When we talk about activity we refer to all sorts of activities: physical, mental, and emotional. It is good practice to balance your physical with mental activities during a day. Remember to prioritise all activities. Ask yourself if you really need to do that activity in that moment. Think if you can do that activity with help from someone else (family, friend, and social help) or in a way that makes it easier to do it and saves your energy (iron while sitting down). Do not forget to include in your daily life activities that gives you pleasure because your emotional state has a big influence on your physical well being.

It will help if you mix the high energy consuming activities with low energy consuming activities during the same day.

### What does break mean?

When we talk about breaks we mean the resting periods which you take between activities, when you are fully relaxed both physically and mentally. You may need to take a break during an activity, so you need to split that activity into small stages.

Resting is different from one individual to another. You have to learn what kind of resting does work for you. It may be more difficult than you think to properly relax your brain, but keep trying until you find your own relaxation way.

Rest does not mean watching television, reading, or listening to music: all these activities require the brain to continue working. Rest is lying down in a quiet, darkened room or you might find rest can be achieved by meditation, or simply focusing on your breathing.

Think of rest as an enjoyable part of your daily life and not as the last resort for your survival.

### How do you know when is too much and stop for a break?

It is very important to establish your personal limit of safety, limit under which you are safe to do things and over which you are in danger to overdo things and get exhausted.

You may want to follow this practice in order to find out your limit: think how long you can do an activity before you need a break, but do only a proportion of what you intended. Continue to do the same amount every day. You may need to keep a diary recording your activity, your breaks and the way you feel physically, mentally and emotionally. After a while analyse the recordings. Is the activity period too long or is the resting time too short? How did different activities impact on you? At the end of this probation period you will be able to decide for yourself how much you can do it without risking of overdoing.

Remember to judge yourself sensibly and impartially! Do not push yourself over the limit! Once you have established your new limit try not to break it until you feel you can confidently sustain it.

### When can I increase my activity?

If your body gets used to this level of activity and you feel ready to gradually increase your activity, you can start doing more, but you need to plan before you start increasing your activity. Be realistic and fair, do not push yourself. Stick with your plan. You may need a few days to get used to a new level of activity. If you encounter difficulties in adapting and symptoms such as pain, fatigue, irritability and distress appear you need to go back to where you were before increasing. It means either you are not ready yet to increase your activity or you have increased it too much.

Do not give up or lose your hope. In case of a setback, analyse what happened and most important why. Learn from your mistakes and build a new strategy for preventing the same thing happening again. When you feel ready try again.

## Who can help you?

You need to be in charge of pacing, because you know your body better than anybody else. It may be very hard at the beginning, but you need to plan, prioritise your activities, set clear goals and stick to the plan. You need to be in control of your body and not vice versa. If you need help to remember to pace, you can use stickers around the house or a diary.

You may get help from Occupational Therapist, Physiotherapist, Psychologist or counsellor when trying to find the correct balance of activity and rest. You may need to address any other problems such as sleeping, pain and changes in your emotional state.

People around you can help by understanding and appreciating that you have changed even if you look the same and that you are trying to deal with these changes. If they do not sympathise with your new way of life, don't feel guilty because you need to look after yourself. You have to learn to say no and avoid people who make unreasonable demands on you.

## Key principles of pacing:

- Plan your daily life and stick to your plan
- Prioritise your activities, do one activity at a time and conserve your energy where possible
- Learn to say no even if it is hard without feeling guilty
- Listen to your body, find out your limits and what works for you and accept them. Discover who are you now and how to get on.
- Remember to pace everything all the time
- Keep a diary of what you do each day including the way you feel as regarding certain experiences.
- Appreciate any positive outcomes rather than exaggerate the negative ones

## Examples of saving your energy

- Wash up while sitting rather than standing
- Use an answer phone if you are too tired to take a call
- Avoid ironing items that really don't need it
- Have your shopping delivered
- Switch off your phone from time to time
- Use equipment that make the job easier such as a blender
- Cooking while sitting rather than standing
- Simplify your environment
- You don't need to watch the advertisement on television, close your eyes and have a rest

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