

Chapter 14

Stamina, Fatigue, and Energy

Recovery from your injuries is a long lasting, time-consuming, and exhausting experience. Your brain keeps you quiet and inactive. Any effort to exceed the set boundaries brings about fatigue. Sometimes seemingly inconsequential behaviors like getting breakfast or taking a shower can bring on the need to nap.

This chapter on "Stamina, Fatigue, and Energy" discusses why you get tired so fast, and how to use rest, pacing, and timed tasks to build your stamina.

ENERGY: Think of the energy you have as if it were a pie. This pie is normally divided into sections according to use. There is Emotional Energy, Cognitive Energy, Physical Energy, and Energy Reserve.

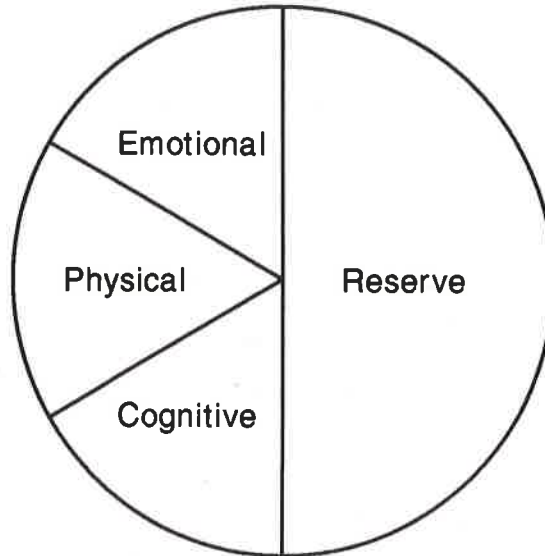


Figure 2: Normal Energy Pie
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Types of Energy

Emotional Energy is generally used to suppress negative thought processes, to modulate emotional responses, and to put the brakes on reactions. When this system is in overload, emotional energy experiences irritability, frustration, anxiety, a short fuse, quick tears, and mood swings. Depression may set in quickly or it may take its time. You will have no reserve for defense.

Cognitive Energy is generally used to comprehend, filter (80% of the brain's energy is used to filter information, mostly in ways which we don't notice consciously), organize, formulate, plan, remember, monitor, and validate responses, and to provide you with a sense of time and place (orientation). When this system is in overload, the brain works slower, less efficiently, and gets disorganized. The filtering process decreases and general confusion may ensue.

Physical Energy is generally used to maintain posture, to reduce muscle tension, to move you about, to fight off illness, to program motor responses, and to inhibit and direct motor responses. It also offers you a sense of your true energy level. When this system is in overload, you may experience fatigue, pain, decreased immunity, and headache, among other things.

Reserve is generally present to provide you with additional support when needed. It lets you know when it is working and lets you know when it is about to run out. It is there to enhance your energy expenditures when necessary and sits quietly by when not needed.

Reserve is generally not readily available following brain injury. You push and nothing may be there. Or you push, getting something and then you pay for it with days of exhaustion. You may not be able to tell when you should stop pushing. Therefore, pacing yourself is essential, even when you think you are feeling good.

Overwhelm is generally present when any of your systems have exceeded their capacity to perform. Those systems which perform automatically, like your physical energy, are at risk. Emotional modulation is, however, the most at risk. Overload will offer inconsistent energy, providing you with good days and bad days. Until you understand how to cope with this, your life will seem out of control and out of your hands. It is true.

Being Tired

When you get to the end of your energy before you get to the end of your day, you get tired. Culturally, getting tired is very uncool. Looking like you are tired makes you a candidate for jokes about vitamins and more sleep. Being chronically tired turns into a label of lazy, anemic or goldbricking. Not pretty.

But tired is what will happen to you with brain injury. The brain uses about 80% of its energy just filtering information and environmental input for you, so that you can think straight under normal conditions. When light, sound, movement, and environmental noise are not filtered for you, you are an instant candidate for overwhelm. When you least expect it, your energy pack will cut out and you will be out of gas. This experience is not negotiable with your brain.

Fatigue

Running out of gas is exactly the feeling one gets. Especially if you add a deserted highway, the middle of the night, and no gas can to the scenario. Oh yes, no money either. Fatigue feels like being stranded. Trying to function in the face of fatigue is grueling.

January 25, 1993: Fatigue: Running Out of Gas

“Brain-sourced fatigue can strike at any time. Pressing on is painful and unproductive. When your mind says “I have to leave (get out of here — stop doing this — stop thinking — I’m overwhelmed — I’m overloaded) now,” believe it, and no matter what Emily Post or the parents-on-your shoulder have to say about it, serve yourself. Leave. Because you are out of gas. And because overwhelm turns to frenzy, frenzy to panic, panic to tears. And you’re just

out of gas. Go hide. It's not your fault. Your brain has shut you down. There will be no more business transacted here today.

You got enough sleep, you're eating right, may have even taken a walk or stretched — this isn't about being tired. This is about pernicious fatigue. The brain can only heal and work simultaneously for so long. Then thinking shuts down in favor of healing. It will last as long as it lasts. There are no tricks for getting a few more miles out of an empty tank. You are closed. Nurture yourself. It could be this way for several years. And strike at any time.

Pacing helps. When I first went back to the office, I went for half a day and took naps between clients. Then, two half-days and so on until I was up to three days a week over a year. Then I tried four days a week, my original pace, and found I couldn't do it. Too much focus, too much energy required.

I wasn't the old me, but the new me. The new me could work three days a week. I decided to restructure my life to finance three days a week. Got an office partner to take my other two days, lowering my overhead from the back door.

Lowered my standard of living, paid off my credit cards, checked out videos from the library, became a coupon clipper. Sold unused household items. Had a spring garage sale. Got a third house mate. Used the pressure cooker more. Made our own pizza. Turned the furnace down and put on a sweater.

Listen to your brain, or you will find yourself on the interstate for no apparent reason. You can't fight back once the fatigue has set in. Your brain will let you heal and improve as long as you listen.

Being a good inner listener is a key to optimal re-emergence. The clues may be subtle at first, but ignoring little clues will earn you a slam dunk "what's your name, your address, how do you get home from here?" Blank. Slam dunk."

Pacing

Once you understand that your resources may be limited, learning to pace yourself can help. The goal is to obtain balanced periods of work and rest. The balance, however, is to your needs. You may find that ten or fifteen minute stretches are what you can manage. You may find that you can work or think or talk on the phone for five or ten minutes, then you have to rest for half an hour or more before you engage in focused thought again. Eventually you may be able to work your way up to forty-five minutes on, fifteen minutes off, throughout the day.

There were times early on when I could either make breakfast OR eat breakfast, but I could not do both. Eventually I paced myself so that I prepared meals that I could then eat half an hour later. I only made the mistake of pouring the milk on my cereal in advance once. Some things you never forget, even with this attention span!

Stamina

Physical stamina develops slowly and pacing helps. I used a kitchen timer to help me keep track of time when I was engaged in activity. Keeping track of time makes you aware of your efforts giving you support to stick with the pacing. And, remember, don't be fooled. Just because you feel great when the timer goes off, doesn't mean there's any reserve there for you. If you keep going you risk fatigue. Then you may have to back up on your pacing and take it easy for awhile again.

Cognitive Stamina

When your brain works consistently, and you feel competent, then your brain function is operating with cognitive stamina. At first you may feel or think inconsistently. Or you may think or feel consistently, but for only 20 minutes. Eventually you will have a good brain day (see the chapter "A Good Brain Day") and feel like a million bucks. Then, of course, you will likely crash and be back to pacing again. I suggest journaling that good brain day so that you can read about it later and have something to work for.

There may be spaces in your continuity of thinking. Rest, exercise, and journaling can help fill in the spaces.

The effort required to build back your stamina can be exhausting too. Small, incremental tasks will build upon one another, and create a matrix of success, however small the steps. Use the same approach that occupational therapists use when returning people to work. It is called "work-hardening". Incremental tasks, performed well, build upon one another. Over time, the length of time and length of competency increase and soon you can sustain activity for half a day, and then for a whole day.

Keep track of your progress, and watch yourself become stronger, more consistent, and more durable over time.

Talking On The Phone

A great deal of cognitive energy is used on the phone. You must talk, listen, sort, evaluate, consider, respond, and hold your attention span all at the same time. Add to that the screening out of your environment, and a phone conversation may take more energy than you have. Time your phone calls. Additionally, screen your phone calls. Just because you are sitting down at home, or even in bed, the energy gets used. Pace yourself. Phone calls count.

Integration Of Gain

Integration of Gain is a fancy phrase which describes the pattern of healing for mild brain injury. Figure three shows that the patient will experience improvement times (progress), plateau times, modest loss of momentum (refueling) and then begin improvement again. Notice the steady overall gain in this model. Remember this model when you experience a bad brain day.

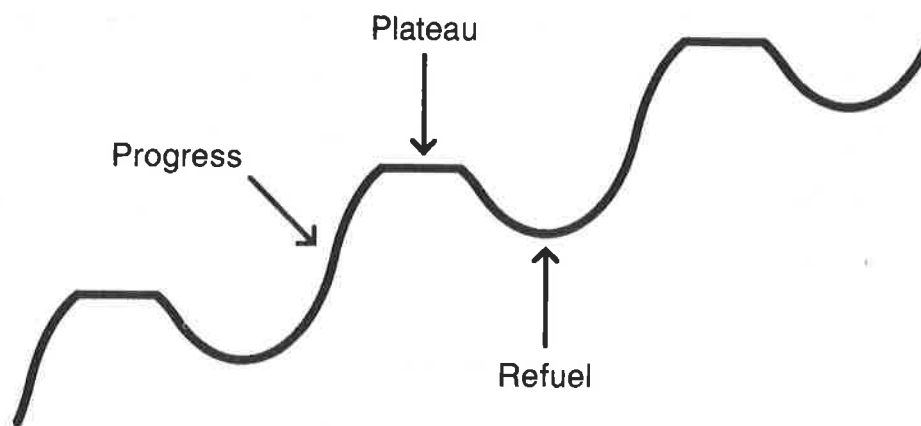


Figure 3: Integration of Gain (The Healing Process)

Relapse: Having a Bad Brain Day

Relapse, or discovering that you are very out of gas, happens. The more you progress and heal the more likely you are to test your limits. The more you progress and heal, the less frequent are the relapses. Hence, there is a terrific shock value when relapse catches you off guard.

May 16, 1995:

"But I was doing so well. Now look at me, lost on the freeway, tears blocking my vision, unable to make sense of a map I've read 100 times, going to a place I've been before. I am hopelessly lost, driving in blinding snow, two hours late. Trembling, I stop to use a pay phone in an industrial area. The phone is broken."

(You may wish to consider purchasing a cellular phone.)

So it seems! Luckily you have a journal. This is a good time to reread the parts about when you could not drive, see clearly, or comb your hair. It is a good time to read or listen to the script entitled "I'm OK Today". (See the chapter "Retrain Your Brain".)

Tomorrow will be better. (Write that down in your journal.) Tomorrow will be better. (Review the above graph for a visual reminder of the healing path.)

Even after three years, I still get a relapse from time to time. It will creep in and bring me to my knees. This happens. Now I just acknowledge that it's a bad brain day and take time to care for myself in this moment. Days like these are particularly entertaining when they are combined with ovulation, changeable weather, or the full moon. (See the chapters "Relapse" and "A Good Brain Day".)

Sleep, Rest, Nap

How you used to sleep (light, medium or log) will be different now. You may require incredible amounts of sleep, rest, and naps. Forget your judgments about napping, and pay attention. The most efficient way for your brain to recover is to make you rest. Your brain will take any chance it can get and will arm wrestle you for the remainder. And your brain will win. When your brain wants you, it will ask nicely once. Your ability to recognize this request will enhance your relationship with your brain. Your inability to recognize this request will result in a losing battle, and tremendous energy expenditure on your part.

Nap as much as you need to, yet monitor yourself so that you are sleeping through the night. If napping interferes with a good night's sleep, you may wish to monitor napping. Some neuropsychologists suggest no more than two naps per day, of 1-2 hour duration unless a full night's sleep can be accomplished with more daytime napping.

October 23, 1992:

"You may not sleep well. You may sleep like a log. At night. And any other time your brain wants you down for a nap. Opposition is fruitless. Any attempt to avoid the nap will result in mental stupefaction, loss of focus, and a tremendous force of will used up in a flash.

If your brain wants you to sleep, then sleep. It's a sign that your brain needs something. It does not mean anything about you. Not a reflection on your responsible nature, your work ethic or the amount of time in your day to complete your artificially invented schedule of tasks. It only and simply means your brain needs you to sleep right now. So listen.

It's a lot like the dentist. If you hold still, open wide, and breathe calmly, this will be over sooner (more like the gynecologist, too, upon reflection).

Being dragged to sleep is a helpless, confusing feeling. Decades of training got you dressed and to the office. The phone is ringing and there are people who have an appointment to see you. You, on the other hand, are sinking fast.

Cancel the appointment and turn off the phone, lie down, and close your eyes. It may be an hour or two, or 20 minutes. It's not failure, incompetence, dereliction or lack of "inner strength". It's a nap. Necessary after brain injury to aid the long-term recovery process.

Holding up old pictures of yourself in your head, remembering who you used to be, trying to be her now, is very painful and destructive thinking. And it doesn't work. So just take a nap. It is as simple as that." (See the chapter "Power Nap".)

The Energy Pie

This next section is provided with permission by Mary Lou Acimovic, M.A., C.C.C., and presents a clear, clinical view of the use of energy by brain injury patients. To me, this is a peek into the knowledge and notes of a Cognitive Rehabilitation Therapist trained to help the brain injured. It is also written in clinical style.

WARNING: If this section is too clinical or hard to concentrate on, you may wish to reread it again six months from now. Ask someone in your support system to read it and to summarize it for you. The main concept here is that you only have so much energy at any given moment, and there is no reserve to draw upon. When the gas gauge reads empty, it's really the truth. (Note: This following section is ideal reading for family members, as it summarizes and clarifies the issues of energy.)

ENERGY ALLOCATION IN MILD TRAUMATIC BRAIN INJURY

Individuals recovering from mild traumatic brain injury report remarkably similar symptoms. Among these, fatigue, or lack of energy, is so consistent as to be almost diagnostic. Even individuals who perform within normal limits on standardized testing, complain of overwhelming fatigue following the effort. A complicating factor is that the fatigue is often attributed to depression which leads to psychological treatment rather than consideration of the fatigue as a condition which predisposes a patient to depression.

(Diagnostic note: Strangely enough, these same mentioned symptoms are prevalent among stressed college student populations. If you were a full-time college student at the time of your brain injury, be aware that you may have had these symptoms beforehand. The brain injury could have enhanced those symptoms.)

Normally, a person is not directly aware of energy expenditure. One becomes accustomed to having adequate energy reserve not only for routine daily activities but also for tasks which are more energy intensive. Rarely does one exhaust the reserve. Phrases such as "at the end of my rope" are commonly used to acknowledge that one is close to running out of energy. A person knows when circumstances will be enervating that would not be disturbing if reserves were adequate.

A person who has sustained a mild brain injury is, however, frequently susceptible to overload. Practitioners who treat these clients know that overload is a word which transcends linguistic boundaries and is immediately identifiable by those who have not yet named their experience. I have found it useful to develop a functional explanation that allows clients with mild traumatic brain injury to put their experience in context and regain a sense of control.

The energy allocation model (referred to by clients as the Energy Pie) describes normal energy requirements in emotional, physical, and cognitive terms. Because many energy-

intensive functions are taken for granted, it is helpful to point out aspects of ones daily life that do require energy or exertion.

The client is alerted to the following COGNITIVE demands:

- ◆ Executive functioning including organization, planning, and follow-through.
- ◆ Language function: comprehension, formulation, and expression.
- ◆ Memory: attentional aspects, storage, retrieval, incidental, and prospective.
- ◆ Monitoring and validating responses
- ◆ Sense of time and place (orientation)
- ◆ Filtering

This last item, filtering, is particularly important. It is obvious from a functional standpoint that the brain must use substantial energy to filter irrelevant information both internal and external in origin. The process occurs to a large extent at a subconscious level. Clients with mild brain injury report increased susceptibility to distraction, reduced tolerance for noise and light, and difficulty concentrating while driving. It is important for them to understand these difficulties in a context which then allows them to manage their environment while working to improve tolerance to distraction.

PHYSICAL energy requirements include:

- ◆ Maintaining posture (Because of physical injuries, clients often need to pay more attention to posture as they can no longer tolerate sloppy habits. Unfortunately, they have less energy to devote to this subtle attentional task).
- ◆ Reduction of muscle tension (Muscle bracing due to soft tissue injury is common in this population).
- ◆ Programming, directing, and inhibiting motor responses (reactions are often slowed).
- ◆ Fighting off illness.
- ◆ Managing pain.

Few clients with mild traumatic brain injury escape the pain of muscle tension residuals.

Our clients are surprised when we inform them that it is normal and healthy to be depressed, given their current situations.

EMOTIONAL energy is required to:

- ◆ Interpret negative thoughts.
- ◆ Formulate emotional responses.
- ◆ Modulate emotional reactions.

It takes energy to regulate oneself emotionally when recovering from a brain injury. An emotionally “healthy” person does not expend energy warding off depression. It is important to realize that your emotional lability may be “without reason” and that if you possessed the energy to regulate the responses, you would. This information is, unfortunately, sometimes in direct contrast to the advice of well-meaning psychologists who aggressively treat the depression as if it were a cause instead of an effect. With brain injury, you may not be able to modulate your emotional body because you simply do not have the energy to do so.

Once a client understands normal energy allocation, it is easy to use the model to demonstrate graphically why functioning is disrupted. The “normal” model shows that one can access reserve consistently, at will, depending upon the requirements of the situation. When an injury is involved, we explain that the normal reserve is tapped on a routine basis. Pain, for example, a common coexisting symptom, drains constantly from available energy. Anxiety over persisting cognitive and physical symptoms is also a significant factor. Cognitive complaints (“slow thinking”, difficulty concentrating, susceptibility to distraction) indicate that more energy is required to perform at premorbid levels both in terms of quantity and quality of work. Practitioners experienced with this population are not surprised when clients report “effort headaches” (“My head feels swollen”, or “my head is

going to explode”) following periods of concentration: indication, perhaps, of increased energy requirements for cognitive tasks.

Because more energy is required for routine daily functioning, less reserve is available for tasks which require additional energy expenditure. One will continue to access reserves when necessary; however, now there is a danger of exhausting resources. When this happens, overload occurs. Quite simply, the system’s capacity is exceeded.

The client is helped to understand that overload can be experienced cognitively, emotionally, and/or physically. Cognitively, clients report “shut down” (“computer is down”), disorganization, confusion (e.g. getting lost, or losing track of a conversation), decreased filtering or increased distractibility. Physically, fatigue is most striking along with decreased tolerance for pain. Clients insist they are sick more often or recover more slowly. Emotional overload is experienced as increased irritability, frustration, anxiety or short fuse, crying easily and for no reason, emotional lability (mood swings).

Once the client understands the principles of energy allocation, s/he is able to improve his/her ability to predict overload. Of course, it is not really that simple. One must also be a good self-observer and reduce symptoms of denial to function efficiently in predicting overload.

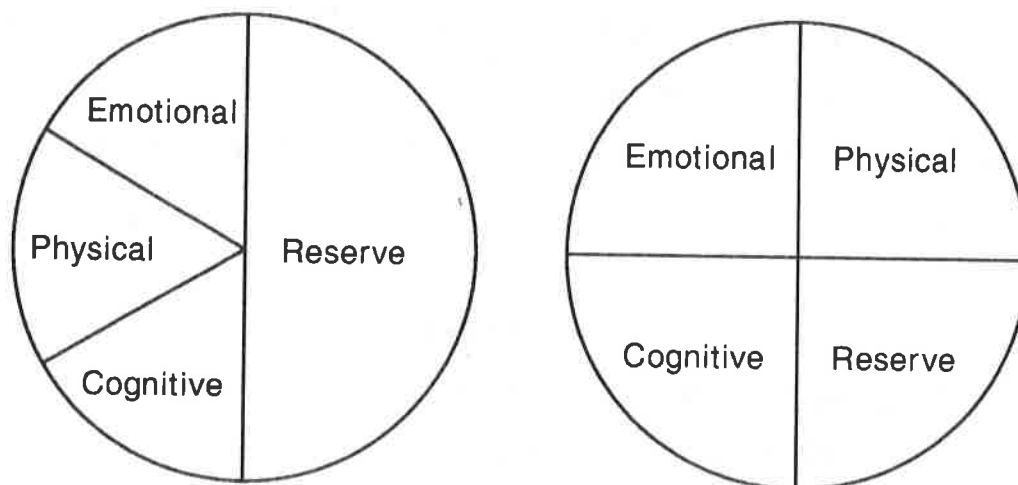


Figure 4: Energy Pie. Normal and After Mild Brain Injury

S/he can begin to assess available reserves, often in concrete physical, cognitive or emotional terms, which allows adjustments in schedule, inclusion of necessary breaks to recharge, and reduction in duties. It is also then possible to help family and friends (as well as therapists who may impose unrealistic demands on the patient) understand the heretofore unpredictable behavior of the client, minimizing unproductive responses. Clients are often frustrated when emotional outbursts occur. When the reason is "overload", the clients response may be discounted, causing further frustration. Treatment can also focus on energy management. Clients can learn how much they are able to do in a certain amount of time based on existing resources. Gradually, they learn to reclaim control over their lives as they recover from this all-too-common and poorly understood injury.

Permission To Sit and Stare

Many days I sat and stared. Too awake to nap, too tired to activate, I would sit and stare. For minutes, sometimes hours at a time my mind would defocus and wander off. I seemed to need that time away. I don't recall that I held thought, processed ideas or visualized or dreamed during those times. It seemed like a wakeful rest.

In privacy this experience is very helpful to the healing process. Practiced at the workplace it may be misunderstood. (Discuss this possible behavior with your workplace advocate.) Be aware that you may sit and stare. Give yourself permission to engage in this behavior. As far as I can tell, it is beneficial in a quiet place. (Obviously, it is not wise if you are driving a car.) Sit and stare all you want. Enjoy this form of rest as you gain energy in your healing process.

Summary

You are your energy pie. Awareness of your energy situation will explain a great deal about your behavior to yourself and others. You only have so much energy, and you do not know how much there is at any given moment. When you feel like you are running out of gas, you are. Believe it and act accordingly whenever possible.

Getting a Good Nights Sleep After Brain Injury



Sleep patterns can change for many reasons:

- Changes in sleep routines due to work, living situation, or family illness or injury
- Changes in your physical health and well-being
- Stress and worry

Good sleep patterns are important so that you have enough energy for all your daily activities (work, home, driving, having a social life). Lack of sleep can affect alertness, concentration and mood.

Here are some simple strategies that you can use to improve the quality of your sleep:

1. Get into a good sleep routine.

- Go to bed only when you feel sleepy at night-time.
- Try to get to sleep at about the same time every day.
- No matter how poor your sleep at night, get up at the same time every day - use an alarm clock.
- Don't oversleep because of a poor night's sleep.

2. Sleep only at night time.

- Sleep during the day will affect your sleep at night so try to avoid naps during the day.
- Early on after an injury, people may find they need to have day-time rest or sleep to manage fatigue, but try to keep the naps short and don't nap after mid afternoon
- If you get tired try to just have a rest on the couch. Don't rest on your bed.

3. Wind down before bedtime.

- Don't watch exciting movies just before bedtime.
 - Do some relaxation exercises
 - Try a relaxation tape
 - Listen to some relaxing music

- Start preparing for bed at least 30 minutes before bed e.g. lock the house, have a shower, put on pyjamas, brush your teeth, turn down the lights.
- Try a warm drink – e.g. milk.

4. Spend time in bed *sleeping*.

- Don't do other activities in bed e.g. reading, watching television, or eating.
- Keep the bed only for sleeping.

If you are awake for a long time:

- Get out of bed.
- Do an activity until you are sleepy (make sure it is something boring).
- Go back to bed – repeat above if needed.

5. Caffeine

- Avoid caffeine after lunch as this may affect your sleep at night-time.
- Caffeine is in coffee, tea, chocolate or cola drinks so be sure to cut down on all of them.
- Try decaffeinated tea or coffee as an alternative

6. Alcohol, drugs, and medication

- Avoid drinking alcohol, especially at night time. Alcohol changes the kind of sleep you have, and can make sleep restless.
- If you smoke cigarettes, nicotine levels may also affect your sleep so try to cut down.
- Some prescription and recreational drugs can change your sleep patterns, so ask for information from your Pharmacist or GP.
- Over the counter medications (e.g. pseudoephedrine) can also change your sleep patterns, so ask your Pharmacist or GP for information about **all** the medications you are taking.

7. Exercise

- Get some gentle, regular exercise because this will help with your sleep.
- Don't overdo it if you haven't been getting exercise for a while. Start slowly.
- Talk to your doctor or a Physiotherapist about the kind of exercise you can do.
- Avoid exercising at least four hours before bed-time.

8. Time outside

Spend some time in the sunshine during the day, because this may help with your sleep patterns e.g.

- Sit outside with a book or magazine or the newspaper (remember sunscreen and a hat).
- Go for a short walk
- Do an activity outside in the fresh air e.g. gardening, walking the dog

9. Sleep Environment

- Make your bedroom and bed as comfortable and pleasant as possible.
- Remove clutter
- Get rid of any noise or distractions e.g. use ear-plugs to cut down on noise.
- Use curtains to block out light and noise and dim the lights.
- Make sure your pillow and bed are comfortable.
- Make sure the bedroom is the right temperature for the weather.
- Essential oils like lavender also can be relaxing, so a couple of drops in your bath water, or on your pillow may help create a relaxing feeling.

10. Be patient.

- It can take time to re-settle sleep patterns so don't expect changes to happen over-night.
- Keep using the new ideas and you should start to see changes gradually.
- If you need further advice, talk to your GP or a Psychologist.

Resources

- See other Acquired Brain Injury Outreach Service (ABIOS) Information sheets at <http://www.health.qld.gov.au/abios/>