NF2 — COPING WITH FATIGUE

People with NF2 commonly report fatigue or extreme tiredness. This often follows treatment for a brain tumour and can continue even after you have fully recovered from the surgery. Whilst there is still uncertainty about the exact cause, there are several theories. Some researchers believe that it might be related to the energy that your body needs to recover from or to fight the illness. Others believe that it might be related to interruptions in the signals sent through the nervous system. A low blood count, sleep disturbances, depression, poor nutrition, infection or medication side-effects can all contribute to these feelings.

The symptoms of fatigue are different from “feeling tired”. Fatigue can begin suddenly, it can be all consuming, naps might not help. It can be physically and emotionally draining on both the person with NF2 and on the family. If you are experiencing this type of extreme tiredness, talk to your doctor as simple tests might identify a problem that can be treated.

Here are some ideas to help you manage the symptoms of fatigue:

- Develop your own “energy conservation” programme. Sort out the really important activities from those that can wait.
- Keep a diary to see if there is a pattern to your degree of fatigue and to work out what activities are triggers.
- Pace yourself through the day, saving the necessary activities for the time of day you have more energy. Forgo jobs that need not be done every day.
- Eat appetite-stimulating foods. Carbohydrates found in pasta, fresh fruits and whole grain breads provide long term energy.
- A moderate amount of exercise might help improve your energy level. Find a friend to walk with. He or she can encourage you to get out when you are tempted to stay in.
- Ask your doctor if your fatigue can be treated by medication. In addition to exploring any new medical treatments for fatigue you will make your doctor aware of the severity of your tiredness.
- When a friend or neighbour asks what they can do to help, tell them!
- Try to get undisturbed sleep. Go to bed at a regular time each day and follow a regular routine. Routine will begin to serve as a signal that it is time for sleep.
- Tell your family, friends & work colleagues so that they can be supportive.

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