



For many people diagnosed with a blood condition, fatigue may become a critical issue in their lives.

Fatigue may influence one's sense of well-being, daily performance, activities of daily living, relationships with family and friends, and compliance with treatment.



Fatigue – more than just tired

Objectives

- Acknowledge that fatigue is an issue
- Improve your understanding of fatigue
- Recognise the symptoms associated with fatigue
- Learn more about how to manage and cope with fatigue



What is fatigue?

Fatigue is often confused with tiredness.

- Tiredness is a temporary condition that occurs after physical exertion and goes away after a good nights sleep or nap
- For a person living with a blood cancer or condition fatigue is often described as an overwhelming daily lack of energy that can affect every aspect of life:
 - Not relieved by sleep
 - Can be acute or chronic
 - Sometimes called the 'invisible' symptom



What is fatigue?

- Fatigue is a subjective experience
- Reported as the most common side effect of cancer treatment
- May come on suddenly
- Can be very overwhelming and distressing
- Not the result of exertion or activity
- Doesn't respond to rest or sleep
- Continues after treatment has finished
- Improvement can be slow and lengthy



"It's like walking through molasses, it's so hard to put one foot in front of another"



"Fatigue affects your ability to concentrate, the emotional strength you need to recover"



Effects of fatigue

"Chemo Brain" or "Chemo Fog"

- Having trouble speaking, thinking or making decisions
- Difficulty remembering things
- Trouble concentrating
- Feeling more emotional than usual
- Short tempered



Effects of fatigue

Fatigue effects everyone differently

- Difficulty with smallest of household tasks
- Feeling of having no energy or strength to do anything
- Feeling breathlessness after only light activity
- Loss of sex drive
- Difficulty sleeping despite the tiredness



Causes of fatigue

Blood Cancers or Conditions

- Great physical strain placed on the body as the cancer establishes itself and competes with the body for nutrients. This can rapidly use up available energy sources (food).

Disease complications

- Such as Anaemia and infections can decrease the body's supply of oxygen and nutrients. The less oxygen or nutrients the body has, the less energy it will produce.



Causes of fatigue

Changes in Daily Routine

- Sleeping, eating and working patterns may change as a result of diagnostic tests, exams, treatments and experiencing side effects
- Relocation for treatment

Emotional Stress

- anxiety, depression, information overload

Treatments

- chemotherapy, radiotherapy, stem cell transplants



Treatment related fatigue

- Chemotherapy
- Biological Therapy
- Radiotherapy
- Stem Cell Transplant
- Metabolic Changes



Treatment and fatigue

- Might not appear until after several weeks of treatment
- While any treatment can cause fatigue, it is more common with combinations of therapy
- Intensity can vary, e.g. peaking a few days after treatment and then declining until the next course
- Usually improves gradually once treatment is over but some find it a long-term symptom



Other causes of fatigue

- Anaemia – shortage of haemoglobin
- Eating problems – not getting enough energy from food
 - Can be due to nausea, mouth ulcers, lack of appetite
- Infection
- Pain
- Depression, anxiety, and stress



Acknowledging fatigue

Talk about it

- Write down questions to ask your doctor at your next visit
- Try not to feel embarrassed when asking someone to repeat or explain something again
- Explain to your doctor and nurses (and family) how your fatigue is affecting you
- Keep a fatigue diary, tracking patterns, triggers and progress
- Take someone with you to your appointments



Acknowledging fatigue

"What a difference it would have made if my fatigue had been acknowledged! What a comfort there would have been ... in knowing that my exhaustion was being monitored."

Maureen Gilbert

A Survivor's Journey: One Woman's Experience with Cancer-Related Fatigue
The Oncologist, 2003

www.theoncologist.com



Managing fatigue

Conserving energy

- Planning ahead is important
- Plan activities throughout the day
- Take short rest breaks between activities
- Accept help from others with meals, housework, etc
- Don't do more than you can manage
- Set time limits on visits/social engagements



Managing fatigue

Restoring energy

- Do things that you enjoy (listening to music, visiting with family and friends)
- Try to do something enjoyable at least 3 times/week
- Regular gentle exercise – walking, swimming, cycling
- Adequate rest and sleep



Rest and sleep

Good Habits

- Sleep just long enough
- Wake up at the same time each day
- Exercise daily if you can
- Reduce noise
- Keep the temperature in the bedroom comfortable
- Have a bedtime snack
- Avoid coffee and other stimulants
- Limit your intake of alcohol
- Don't over do daytime rest, as can disrupt your sleep



Rest and sleep

What can you do if you can't sleep?

Mind occupiers:

- Try to remember the lines of a poem or song
- Make alphabetical lists of countries, names, etc.
- Relive a favourite experience in every detail
- Write mental letters
- Relaxation exercises

- Sleeping tablets may be an option



Coping with fatigue

Child care

- Explain to your children how you are feeling
- Plan activities with your children that can be done sitting down
- Don't lift smaller children - use a pram
- You may be able to involve your children in some household chores
- Accept help from trusted friends and neighbours to look after your children



Coping with fatigue

Work

- Working part-time
- Changing your hours so that you can travel to and from work at less busy time
- Finding you a parking place near to your place of work
- Allowing you to work from home, if possible
- Finding you lighter work if your job involves physical exertion or heavy lifting



"Wake up Harper, it's five o'clock - I don't want you putting in for overtime."

Nutrition

Maintain good nutrition

- Include protein in your diet – best sources are dairy, eggs, red and white meat and seafood, soy bean, lentils and nuts
- Appetite and taste changes – try new foods
- Drink plenty of fluids
- Manage nausea and vomiting
- Ask to be referred to a dietician if required



Exercise

- Research has demonstrated the benefits of exercise while you are having treatment and it doesn't matter what exercise - if any - you have done in the past.

"You know, I feel better.
You know, I figured I'd do something positive for myself and you know, it made me feel good."



Exercise

- Start slowly and gently
- Have a regular exercise programme
- Exercise is known to improve nausea, fatigue and mood



Relaxation

Relaxation helps to relieve tension and recharge your batteries

- Relaxation tapes
- Physical relaxation techniques
 - Body awareness – concentrating on different body parts
 - Breathing exercises
- Mind relaxation techniques
 - Imagery exercises



Psychological Support

- Talk to your doctor and nurses about fatigue
- Talk to other people with fatigue
- LBF Support Services Coordinators
 - Experienced haematology nurses who provide:
 - Emotional and Practical Support
 - Information and Education
- Counselling may also be beneficial



Caregiver fatigue

Care for the Carers!

- Take time out for yourself
- Ensure you have adequate sleep and rest breaks
- Identify times when you have the most energy and arrange activities such as having family around to visit and shopping at these times
- Learning to say 'No' and 'Yes' at the right times



Fatigue Stats

- Of 29 patients who had bone marrow transplants, 50% reported moderate-to-severe fatigue more than 1 year after transplant. Fatigue was one of the three most negative items studied and had an impact on quality of life more than any other physical problem
- Of 90 patients with a diagnosis of lymphoma, 33% reported a lack of energy at a median of 32 months after diagnosis
- Of 403 individuals with Hodgkin lymphoma, 37% reported their energy levels had not returned to levels that satisfied them even after a median of 9 years post treatment





Keep your chin up!

- Fatigue is real
- Fatigue is normal
- Fatigue is a common side effect of treatment for cancer or other blood conditions
- Fatigue cannot be cured but it can be managed
- Energy is gradually regained