

Information leaflet for Families, Children  
and Young People with Epidermolysis Bullosa

# Fatigue Management and Pacing



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## What is Epidermolysis Bullosa?

Epidermolysis Bullosa (EB) is a rare, incurable genetically inherited skin condition which causes fragile skin that can blister as a result of trauma or friction. There are different severities of EB and in some cases there is fragility and blistering of the internal mucosa as well.

## What is Fatigue?

Fatigue is a feeling of constant exhaustion which can affect a person both physically and mentally. It generally presents as an individual having a lack of energy and it can also impact upon a person's motivation. Fatigue is different to drowsiness or sleepiness which refers to a person's need to sleep. It can often be the case that a person is unaware of their low energy levels until they try to complete a task they completed in one-time frame with another.

## EB and Fatigue

Fatigue can happen for a number of reasons including lifestyle choices, physical health or even mental health issues.

Fatigue has also been linked with the presence of another medical condition known as anaemia. Those who suffer with EB, particularly more severe types of EB (Recessive Dystrophic Epidermolysis Bullosa and Junctional Epidermolysis Bullosa) have the potential to develop anaemia.

Anaemia is caused by low red blood cell production within the blood which reduces the amount of protein (known as haemoglobin) to effectively carry oxygen to the body's tissues which helps us to produce energy.

Children and young people with EB can suffer from three types of anaemia including:

1. Iron deficiency – blood and iron (a mineral within blood) loss through wounds.
2. Chronic inflammatory anaemia – recurrent chronic infections causing inflammation which prevents red blood cell production.
3. Nutritional anaemia – Due to the effect EB can have on the gastrointestinal tract, nutrients become hard to absorb. Certain foods can also be difficult to chew and swallow if there is blistering to the mouth or teeth are painful.

Symptoms of anaemia can include:

- Reduced appetite;
- Weakness;
- Fatigue;
- Weight loss;
- Tiredness ;
- Irritability;
- Reduced immunity;
- Poor wound healing.

## **Why is nutrition important and linked to the treatment of anaemia?**

Nutrition and a well-balanced diet are both important in managing the effects of anaemia.

Due to the nature of the condition, children and young people with EB may need to eat more protein rich foods and increase their calorie intake. This will help their body

to restore tissue and replace fluid and protein which is lost through blistering.

Maintaining a well-balanced diet will also help with managing fatigue and maintaining energy levels.

## **Fatigue Management**

Although fatigue is not always easy to get rid of, there are strategies and coping methods which can help to reduce the symptoms and help an individual gain more control over their day to day lives. There is not one strategy that will suit everyone and it takes time to find what works best for the individual. It might be an idea to keep an activity diary for a week to identify key trends and pin point times of when fatigue can be particularly worse.

### **Why is fatigue management important?**

Fatigue management is important as it reduces the amount of energy wasted which can affect independence and safety. It also helps to reduce pain for an individual which can be felt both physically and emotionally and impact on a person's confidence.

## **Occupational Therapy and Fatigue Management**

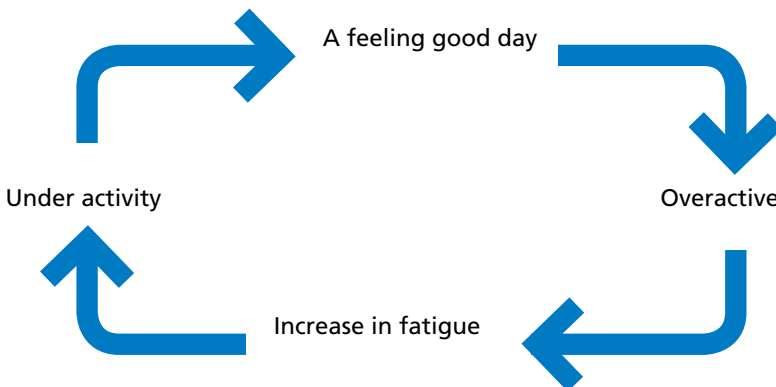
An occupational therapist's main aim is to allow an individual to be able to participate in meaningful activities in order to engage within society. Fatigue can interfere with a person's ability to participate in their activities of daily living which is something we want to problem solve together. By providing someone with the knowledge of their fatigue and the tools that can help to manage it, we can limit the impact fatigue can have in day to day life.

When trying to identify ways which can help with energy conservation, just remember the three 'P's:

## Pacing

This corresponds to your productivity through energy level awareness by slowly building up activity over time.

The 'Boom and Bust cycle' nicely explains what can happen when we do not control our energy output. We can get stuck in a pattern where we do too much activity when we feel good, and our energy levels are high with the aim of being as productive as possible - this is known as the 'Boom' stage. When this occurs, we may not realise that we have done too much and enter a stage of under activity as our energy levels are reduced and we are unable to recover quickly. We call this the 'Bust' phase which can reinforce a loss of physical strength.



(Action for m.e: 2013)

Pacing allows you to take back control and start on a steady daily routine.

### **What can be done?**

- Do not fill your day full of activity;
- Avoid rushing;
- Spread tasks over time throughout the day;
- Stop before becoming too overtired;
- If required, separate tasks over two days;
- Alternate tasks which are demanding in between less demanding tasks.

### **Prioritising:**

To help avoid and reduce the impact of fatigue, identify what are the most important tasks for the day or the tasks that you really want to do. This can help conserve energy and improve performance. When trying to identify what is important, ask yourself the following questions:

- Does it need to be done today?
- Does it need to be done tomorrow or even at all?
- Can anyone help me complete this task?
- Is the task manageable?

From this you will be able to identify what are the most important activities for the day. It is also important to remember to set yourself realistic and achievable goals and to set meaningful tasks to encourage engagement and promote confidence.

## Planning:

Once you have singled out what your priorities are for the day, you can start to plan how best to complete these tasks. This helps you to best plan your time and include times to rest into your day. You can think of ways to try and help reduce energy loss by:

- Pin pointing the best time of day to complete a particular task, such as meeting up with friends maybe better in the morning rather than the afternoon;
- Keep a list or diary log of what needs to be done and stick to that list;
- Break down a long task into stages and complete a little and often, such as when getting ready for school you might want to wash your face and brush your teeth first, sit down, have a break and eat your breakfast and then continue by getting dressed
- Think ahead to what is next and try to find a balance between demanding and less demanding tasks, such as completing written pieces of homework with regular breaks in between may help with any pain as well as mental and physical tiredness;
- Organise the timing of each task and avoid any needless trips. If you need to collect items from around the classroom for a work project, identify what you need and where they are located and collect items that are closely stored at the same time to avoid having to go back up and collect individual items.



## Pacing and the Environment

Sometimes making small changes to your home and school environment can help with effective use of your energy. Think about:

- Keeping items that you regularly use close, such as keeping all essential items needed for a particular lesson within reaching distance;
- Keep your homework and learning spaces uncluttered;
- Keep anything that is slightly heavier to lift at a lower level and anything that is slightly lighter, at a higher level - such as keeping your school bag at a lower level so it is easier to lift;
- Make sure you have good lighting and ventilation;
- Adopt a good posture in the classroom which promotes a straight back with hips and knees at 90° angles, feet flat on the floor and work at table height that supports a level comfortable to rest elbows;
- Consider the tools you use for daily tasks; would they benefit from being lighter or larger? For example, larger handled cutlery made from foam or the use of chunkier pens in the classroom.
- Can some parts of a task be completed whilst sat down like when getting dressed or cleaning your teeth?

## Looking after and sharing information about your child

We have a duty of care to help patients and families understand how information about them is kept and shared and we include the following information in all our patient leaflets:

Information is collected about patients relevant to their diagnosis, treatment and care. We store it in written records and electronically on computer. As a necessary part of that care and treatment we may have to share some patient information with other people and organisations who are either responsible or directly involved in the patient's care. This may involve taking the patient's information off site. We may also have to share some information for other purposes; such as research etc. Any information that is shared in this way will not identify the patient unless we have the patient's and parent's/carer's consent. If you have any questions and/or do not want us to share that information with others, please talk to the people looking after your child or contact PALS (Patient Advice and Liaison Service) on 0121 333 8403.

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**Birmingham Women's and Children's NHS Foundation Trust**  
Steelhouse Lane Birmingham B4 6NH  
Telephone 0121 333 9999  
Fax: 0121 333 9998  
Website: [www.bwc.nhs.uk](http://www.bwc.nhs.uk)

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Produced: May 2017  
Review Date: May 2021  
Version 1.0.0  
CPADS:

