

# Tiredness after PIMS

After being in hospital with PIMS, children can feel tired and have cognitive difficulties (not being able to concentrate for long). These get better with time, but children need to find an energy balance and establish good energy patterns.

Children can find some activities more tiring than others. It is important for them to think about how they feel after each activity, and change their habits to help themselves. This is described later on.

These are the issues that we expect to get better with time:

- Reduced school attendance
- Reduced concentration in school
- Memory problems
- Not enjoying playing in team sports
- Tiredness after walking, or climbing stairs
- Being too tired to socialise
- Having some bad days after good days

All activities use energy, and most of them use a combination of activity types. The types of activity are:

- physical (sports, climbing stairs)
- cognitive (reading, school work)
- social (conversation, playing games)

## Balancing energy

After leaving hospital after PIMS, many children have less energy than they did before their illness. To return to their previous energy levels, children need to be aware of what uses up their energy, and which activities make them feel energised. They should 'fill their energy battery' with things that give them energy, and do less of the things that take their energy. They should also aim for a healthy energy pattern (see below).

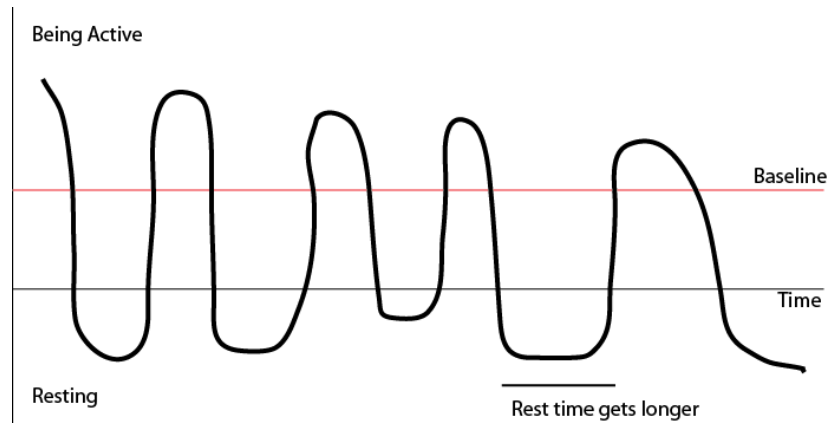
Things that give energy	Things that take energy
<ul style="list-style-type: none"> <li>• Rest</li> <li>• Self care</li> <li>• Food</li> <li>• Sleep</li> <li>• Exercise</li> <li>• Mental stimulation</li> <li>• Socialising</li> </ul>	<ul style="list-style-type: none"> <li>• Worry</li> <li>• Academic stress</li> <li>• Conflict</li> <li>• Commitment pressures</li> </ul>

## Energy patterns

### Boom and bust

We see this pattern in people who have tiredness after being unwell. It involves fluctuating patterns of overactivity and underactivity.

It is tempting to do more on a good day or when you have important things, like school. But this can make you feel worse or mean you need time to rest. Gradually, the time you need to rest after an activity can get longer, and your overall average activity levels can decrease.



### Stuck in the mud

This is when people significantly reduce their activity levels due to their tiredness, for example by not doing any exercise or going to school. Exercise, mental stimulation and socialising are on the list of things that **give** energy. These things can be gained from going to school. Children who do not exercise or attend school, even for a short time on a bad day, risk getting into this cycle of low energy.

### Baseline and pacing

It's best to aim for this energy pattern. Our baseline is the amount of activity we can do without making tiredness worse. Pacing allows us to engage in activities little and often to build up activity levels over time, avoiding the above patterns.

For example, if your baseline for walking without having worse symptoms is 5 minutes, you can take breaks after 5 minutes of walking, and slowly build up your baseline over time. This applies for any activity. You can then move on to more intense activities like football training.

Tips for pacing:

- Spread activities out over more time
- Break up tasks or school work into manageable chunks
- Stick to your planned limits **even on a good day** when you might feel like you could do more
- Try to do some light activity **even on a bad day**
- Do not focus too much on one kind of activity
- Take regular breaks
- Sleep well
- Prioritise important tasks for good days

It can be helpful to keep an activity diary. You should write what activity you did, how long you did it for, and how your energy level felt afterwards. You can highlight activities that need the most amount of energy in red, medium amounts in yellow, and relaxing activities that help you recharge in green.

Almost everyone knows the story of the tortoise and the hare. They were in a race where the slow and steady approach taken by the tortoise helped him to beat the hare who used up all his energy earlier in the race by sprinting.

## Sleep

Do	Don't
<ul style="list-style-type: none"><li>• Wind down before going to bed, by doing calm, relaxing activities</li><li>• Only use your bed and bedroom for sleep</li><li>• Aim for a routine, trying to wake up and go to sleep at the same times each day</li></ul>	<ul style="list-style-type: none"><li>• Try not to sleep in the day as it can make it harder to sleep at night</li><li>• Have caffeine (coffee, sports drinks or cola) after midday</li><li>• Use your bedroom for stimulating activities</li></ul>

### Contact us

If you have any questions or concerns about PIMS please contact our infectious diseases nurse, **email** [evelinakdpims@gstt.nhs.uk](mailto:evelinakdpims@gstt.nhs.uk), **mobile** 07598 552683 or 07468 700165, **phone** 020 7188 4679 (secretary), Monday to Friday, 9am to 5pm. Out of hours, please contact NHS111.

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit **web** [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)

### Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline, **phone** 020 7188 3003, Monday to Friday, 10am to 5pm **email** [letstalkmedicines@gstt.nhs.uk](mailto:letstalkmedicines@gstt.nhs.uk)

### Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS), **phone** 020 7188 8801 **email** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk). To make a complaint contact the complaints department **phone** 020 7188 3514 **email** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

### Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch, **phone** 020 7188 8815 **email** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

### NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day, **phone** 111 **web** [www.111.nhs.uk](http://www.111.nhs.uk)

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