

# Rehabilitation: self-management of long COVID for adolescents

#### Who is this leaflet for?

This leaflet provides advice and support for young people aged 12 years and older who are experiencing symptoms of post COVID-19 condition, commonly known as long COVID. It aims to help you to understand and manage your condition and ask for help and support.

You may find some sections of this leaflet more relevant than others – just read the ones that are most helpful to you. You may wish to share the leaflet with a trusted adult, like a parent or guardian.

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## What is long COVID?

Long COVID is the term commonly used to describe the presence of ongoing symptoms and signs that last for 3 months or more after COVID-19 infection. There is no specific test for long COVID and it can take some time to diagnose.

Common symptoms and signs of long COVID are:

- ► fatigue (feeling very tired and not getting better with sleep, low energy, too tired to hang out with your friends);
- symptoms that get worse after activity (also known as post-exertional symptom exacerbation, or PESE, for short);
- headaches;
- ▶ light-headedness or dizziness, especially when you stand up (this is also known as "orthostatic intolerance");
- ▶ problems concentrating at school, reading and remembering things, or trouble thinking of the word you want to say (also known as "brain fog");
- ▶ finding it hard or effortful to breathe (also known as "breathlessness");
- changes in your sense of smell and/or taste;
- anxiety (feeling worried about things);
- low mood (feeling a bit sad, grumpy or angry);
- problems with sleeping (having trouble falling asleep or waking during the night);
- tummy problems such as nausea (feeling sick) or tummy pains, or changes in your poop (being constipated or having diarrhoea);
- muscle or joint pain;
- ringing in your ears or being sensitive to noise;
- sore throat or voice changes or trouble with swallowing;
- heart palpitations (feeling your heart beating fast);
- ▶ fever; and
- skin rashes or changes in the colour of your skin.

**Symptoms** are things you feel or notice yourself, like pain or fatigue

**Signs** are things that other people notice and things that can be measured, like body temperature or skin rashes

Symptoms can get better, get worse or change over time. You may find it difficult to do all the things you normally do, such as taking a shower or bath, getting dressed, going to school, learning, playing sports, enjoying hobbies or hanging out with friends.

Asking for help and telling someone about your symptoms is important. However, sometimes it may be difficult. You can start by talking to friends, family or a trusted adult. Your symptoms may improve with rest and time, and there are some things you can do to help manage them. We call this "self-management". It's important for you to seek support from doctors and other health professionals.

## When should you seek immediate advice?

Certain conditions can develop after COVID-19 illness that doctors and health professionals need to know about. Your parent or other trusted adult can help you to seek advice. It's important to tell them if you experience any of the following symptoms:

- > you have difficulty breathing, or you become very short of breath when doing a small amount of activity;
- you experience chest pain, a racing heartbeat or dizziness (this may happen when you stand up or change positions or during exercise/certain activities);
- you notice you are becoming more anxious, worried, depressed or sad, or you have thoughts of harming yourself or others.

## Understanding post-exertional symptom exacerbation, or PESE

- ▶ With long COVID, you may find that you need more rest and sleep, and/or that your symptoms get worse after exercise or other activities. When your symptoms get worse a day or two after the activity, this is PESE. PESE can happen if you do too much physical activity, but it can also happen if you do too much brainwork or too much socializing, or sometimes it even happens after you are really happy, sad or angry.
- ▶ Finding the balance, or "pacing yourself" finding out how much activity you can safely do and how much rest you need can help you to manage your symptoms. It can be frustrating when you cannot do all or some of the activities you enjoy. Pacing takes practice, but it can be helpful to avoid PESE and to manage your symptoms.

### Pacing

- ▶ Pacing is a way of balancing activity and rest. Balancing activity with rest can help manage your overall symptoms and avoid dips in energy that may mean that you need more rest or sleep later. Sleep and rest are important for your recovery. However, too much daytime sleep can disrupt your night-time sleeping pattern.
- ▶ Keeping an activity and symptoms diary can help you to understand when your symptoms get worse and when you need to rest, and thus help you to pace more effectively. You can also use it to monitor changes over time, see the impact of your medication or daily routine, or decide when you are ready to try spending more time at school. A trusted friend or adult can help you to fill out your activity tracker. See page 14 for a blank activity tracker you can fill out.
- ▶ With pacing, it is useful to include both activities that you "need" to do, such as eating, washing and dressing, and those you "want" to do, e.g. hobbies. Schedule rest periods as needed throughout the day, including taking a break from the television, phone, tablet or other screens, to give your brain a good rest. Even light and noise can make you tired. Doing some deep breathing while lying on your bed, listening to calming music or spending time in nature, such as in a park or forest, may help you to relax and rest.

## Managing activities of daily life

Your body is like a cellphone battery. Sometimes it is fully charged in the morning, but other days it is only partially charged. When this happens, you cannot do as much as you would normally do in a day. It's best to take breaks and stop activities before your symptoms, including exhaustion, get worse.

Activities can be broken down into three groups:



physical tasks may include sitting upright, standing, climbing the stairs, baking a cake, walking to school, playing outside, playing sports or riding a bike;



thinking ("cognitive") tasks may include concentrating on schoolwork, reading a book, watching a film or texting with your friends; and



social activities may include visiting friends, playing video games or having a good laugh.

Some things may help your long COVID symptoms. Each person's experience is different, so you may need to adjust them to your own situation and find the ones that are good for you.

#### Find your baseline

Your baseline is the amount of activity you can do without causing a flare-up in symptoms. To establish your baseline, try to identify the amount you can usually do without causing a flare-up, rather than the amount you can do on your best days.

**Examples:** on a regular day, it takes an hour and a half (90 minutes) for you to get ready in the morning (getting out of bed, getting dressed, eating breakfast, etc.) because you need to rest between each task. This is your baseline. On a good day, it may take less time, and on a bad day, it may take more.

You can always adjust your baseline if you think you have set it too high or too low. An activity tracker like the one on page 14 of this leaflet can help you establish your baseline.







## How to gain energy

Have a good night's sleep

Manage pain

Balanced diet/eat often

Drink enough water

Short frequent rests

Mindfulness/meditation

Leave some energy spare

Ask for help to do things

Use equipment to help

Do activities sitting down

Know what takes up energy

Medication to aid symptoms

Avoid overdoing it

Stabilize temperature

## Sensible energy use

Plan your day/week/month

Be flexible/have a back-up plan

Break activities into small parts

Take mini-breaks in activities

Alternate easy and hard activities

Do what makes you happy

Learn what is most important

Rest before you need to

Spread your energy use out

Learn activity energy demands

Have regular quiet rest days

Balance brain and body energy

Use equipment/help as needed

Match activity to energy

## **Energy** drains

Having a bad night's sleep

Staying up too late

Not eating enough

Making poor food choices

Not drinking enough

Issues going to the toilet

Side-effects of medication

Doing too much or too little

Unmanaged symptoms

Anxiety and worry

Infection/illness

Being too hot or too cold

Extreme emotions

Unmanaged pain

#### **Cautious return to activity**

When you feel that your energy level is improving, slowly start adding new activities. Choose some that you need to do, and some that you want to do. It is important to listen to your body and stop the new activity if your symptoms worsen.

### Tips for thinking (cognitive) self-management strategies:

use alarms or reminders on your phone to help you remember important things like taking your medications;

focus on one activity at a time and minimize any distractions – for example, study in a calm and quiet space;

break down activities into smaller chunks and do one small task at a time; and

draft your answers to study questions in bullet points first, before worrying about full sentences or essays.

#### Tips to slowly increase physical activity levels:

begin with a small amount of light activity (such as walking around the house) that you can perform regularly (not just on a good day) without increasing your symptoms;

try a new activity like showering, dressing or preparing breakfast;

make sure to wait a few days to see how your body responds before you try a new activity again;

try activities that take different lengths of time to determine what is manageable for you;

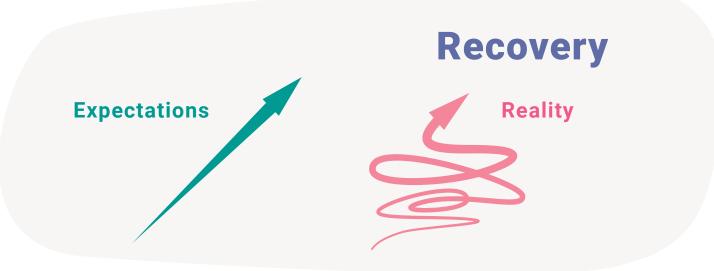
when you feel that you can do activities regularly without increasing your symptoms, you can slowly add more activities, or do the old activities for longer; and

if you feel dizzy standing up, but better when you sit down again (also known as orthostatic intolerance), it may help to begin physical activities or exercises while lying on your back or tummy or while sitting – do a few exercises at a time, slowly, then gradually go more upright; if you experience ongoing symptoms of dizziness or light-headedness after standing up, it is important to contact a health professional for further assessment.

Note: If your symptoms do not settle down in a day or two, or get worse, your baseline may be too high and you need to back off or slow down. This is not your fault. Learning about baselines and how to pace yourself is difficult. Consider getting help from a health professional if you are unable to get the balance right!

#### **Getting support**

It's important to remember that progress is not a smooth, straight path and is different for each person. There will be ups and downs, better days and worse days. Sometimes you may feel you are taking two steps forward and one step back; but remember, this is still a step forward in the overall process. Talk to your family, friends or school, so they can support you in your activity management and recovery.



#### Managing breathlessness

With long COVID, you may experience breathlessness, which is an unpleasant feeling of uncomfortable, fast or difficult breathing. Breathlessness can be a sign of more serious medical problems; therefore, if you are experiencing breathlessness it is important to seek an urgent review by a medical professional. Once you have the OK from the medical professional, this section suggests some things that you can work on to help manage these symptoms.

**Observe your breathing pattern:** before starting breathing exercises, it is important to observe your breathing pattern, like this:

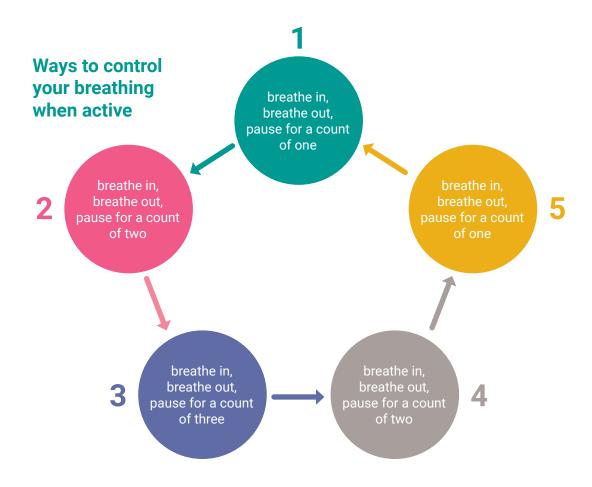
- ▶ set a timer for 2-5 minutes;
- ▶ sit or lie down comfortably, with one hand on your tummy and the other at your chest;
- > your breath out should be longer than your breath in. While observing your breathing, ask yourself:
  - · am I breathing through my nose?
  - am I breathing down towards my tummy and lower ribs?
  - · is there a gentle rhythm to my breathing?
- ▶ take time to stretch and adjust your position if needed.

#### **Breathing exercises**

Practising slow, deep breathing, as described above, helps to improve well-being and can be calming.

Ways to stop yawning, sighing, throat-clearing: when you feel a tickly sensation or a cough, or the desire to yawn, sigh or take a deep breath, try one of these:

- put your fingers on your lips
- ▶ tip your chin down and swallow
- gently breathe out slowly
- ▶ take in slow, small breaths through your nose for 30 seconds
- ▶ sip some water
- let your breathing settle to normal.



**Pursed lip breathing:** if you are feeling very short of breath, a quick way to get control again can be to do one or two sniffs in through your nose followed by breathing out through pursed lips (as if you are trying to whistle or gently blow a candle out on a cake). This helps you concentrate on the out-breath rather than the in-breath – which is important for getting back control.

Ways to help control your breathing when feeling anxious or worried: find a quiet space, take 2–5 minutes out of your day. Sit or lie down comfortably. With each out-breath, relax your body into the floor or chair. Work from your feet up to your head – think about each body part, notice if there is any muscle tension, and then with each out-breath try and focus on letting go of that tension and relaxing your muscles. Then bring your attention to your breathing; use the ticking of a clock or the slow beat of relaxing music to slow your breathing.

**Note**: as you try to make changes to your breathing it is really common for it to feel unnatural, uncomfortable and hard work to keep the changes going for more than a few minutes at a time. This is to be expected, but it does improve with practice.

#### Managing mental health: feelings, emotions and stress

It's very common for anyone with health challenges to struggle emotionally with their symptoms and the adjustments they have to make to their lives. Understandably, this can have an impact on your mood. You may experience feelings of:

- anxiety (worry or fear) about your recovery or future, or about how to recover, worries about missing school, or generalized anxiety without a specific reason;
- ▶ frustration about not getting better quickly enough or not being able to keep up with friends;
- apathy (lack of interest in things that usually interest you);
- ▶ persistent sadness or low mood about not being able to participate in your regular activities or social interactions, feeling worthless, thinking about harming yourself or others;
- ▶ anger or feelings of unfairness that this is happening to you; and
- ► stress (see below).

All these emotions are a normal response to such a drastic change in your health. They are not the cause of your long COVID; they are the way you respond to your experiences. Proper management of these emotions is a meaningful part of your health plan.

#### What you can do

If you are experiencing feelings of anxiety, frustration, sadness or stress, there are things you can do to help. Remember that everyone is different, and different things work for different people. Here are some examples of things that can help:

- try to spend time with other people;
- don't keep your feelings or worries to yourself, even if they seem small or silly talk to people you trust or write down what you are feeling;
- move your body in some way, even if this is just a short walk outside, breathing exercises or a few stretches;
- ▶ limit the amount of time you spend on the internet and looking up symptoms; and
- ▶ if your feelings or worries seem to be spiralling out of control, paying more attention to the "here and now" may help one way to do this is by using a grounding technique (see below).

#### **Grounding technique**

Take slow gentle breaths and ask yourself:



#### **AHA** technique

When you are experiencing emotions such as anxiety, frustration, sadness or anger, try to identify and reflect on the thoughts that led to those feelings. Using the Accurate, Helpful, Alternative (AHA) technique allows you to change your perspective on the situation.

For example: a young person with long COVID experiences a crash (extreme fatigue) after trying to return to school and may think: "I'll never get better and make it back to school".

- ▶ Is this thought accurate? No I cannot make long-term predictions of how people with long COVID might improve over time.
- ▶ Is this thought helpful? No it just makes me want to give up and stay in bed.
- ▶ Is there a more helpful alternative? Yes maybe I tried to do too much too soon and I need a slower-paced plan to get me back to school and hobbies.

#### When to reach out for help

Emotions and stress are a normal part of life, especially when dealing with a challenging situation. However, at times these normal reactions can transform into mental health difficulties that require help. Here are some things to look out for:

- ▶ feeling too anxious, worried or nervous to do things that you can usually do;
- ▶ not looking forward to or enjoying the activities you usually like;
- ▶ feeling so low or sad that it is difficult to manage daily activities like getting out of bed;
- feeling that you are sad more often than you are feeling okay;

- feeling or thinking about hurting yourself or others;
- ▶ thoughts or worries that cause you difficulty in sleeping or wake you up very early in the morning; and
- using alcohol or drugs to make yourself feel better.

If you are experiencing any of the above feelings, it is important to speak to a trusted adult about it. Together you can then decide whether to involve a medical professional to get more help with your mood. If you feel you are unable to ensure your own safety, it is important to seek help immediately.

Your friends and social life are important for your general well-being. Stay in regular contact with friends as much as you can.

#### **Managing sleep**

Problems with sleeping often occur in people with long COVID. Some people have difficulty falling asleep or wake frequently during the night, while others could sleep all day. Sleep is important for improving your energy levels and well-being.

Below are some strategies for improving your sleep patterns and sleep quality. Remember to be patient and practise strategies consistently for 2–3 months, as it can take a while for change to happen. Seek advice from a health professional if you feel you need support.

#### Routine

- ► Go to bed and try to wake up at the same hour every day, even on the weekend.

  Note: if getting up at your usual time means you have no energy to do anything during the day, some people find that extra time in bed in the morning can help them have a window of energy in the afternoon.
- ▶ Make a daily or weekly timetable of your activities (see section Find your baseline).
  - Try to reduce or avoid sleeping during the day, as it can disturb your sleep/wake cycle.
  - If you find it difficult to sleep at night, you may need to reduce or avoid sleeping during the day, as it can disturb your sleep/wake cycle. If you really need to sleep in the daytime, aim to limit naps to 20–30 minutes and use an alarm to help. Remember it can take time to see changes; practice can help create change and manage your symptoms.
- ▶ Limit screen time (TV, tablets, phones and computers) take regular breaks.

#### **Environment**

► Make sure to have as much daylight as possible when awake, and have your bedroom dark and quiet at night when you go to sleep.

#### In the morning

- ▶ If you experience fatigue, it can be helpful to set your alarm around 30 minutes before you need to be out of bed, and slowly wake up.
- ▶ Do some quiet activity, such as listening to music, to help wake you up.
- ▶ If possible, open the curtains, as bright light helps you to wake up.
- ► Try to get dressed in regular clothes for the day, even if you don't have much planned wearing nightwear can make your body think it's time to relax and go to sleep.

#### In the evening

- ► Try to create a consistent evening routine, e.g. start by brushing your teeth, then put on your pyjamas, do breathing exercises, and then go to sleep.
- ► Avoid eating late at night if you can.
- ▶ Switch off screens 1–2 hours before bedtime.
- ► Avoid too much activity just before bedtime.
- ▶ Rotate your clock so it is positioned away from the bedside.
- If your mind is full of ideas and thoughts, write down your thoughts before you try to go to sleep, so that you can deal with them in the daytime.

#### Managing eating, including smell and taste problems

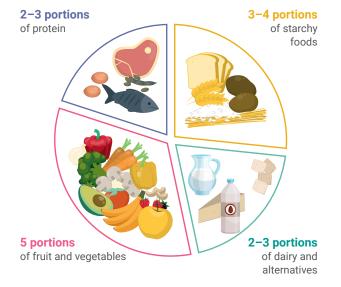
When living with long COVID, you may have symptoms such as tummy pain, feeling sick (nausea), or loss of smell and/or taste. All these can lead to a change in your appetite and how you experience food. A healthy diet is important for managing energy levels and for recovery, so a regular eating pattern with nutritious foods should be a goal to work towards.

Some suggestions for when your appetite or eating patterns have been affected:

- ▶ aim to have three meals a day plus 1-2 healthy snacks if you struggle to eat large portions, then aim for more frequent but smaller meals;
- ▶ if you are feeling sick or if certain foods taste strange to you, plainer foods such as toast or crackers may be easier to manage;
- ▶ cold foods are less strong-smelling than hot foods and may therefore be easier to eat; and
- ▶ follow a healthy, balanced diet (see below).

#### **Healthy diet**

Each day you should try to eat:



A portion is measured as the amount of food that will fit into the palm of your hand.

It is important to stay well hydrated (i.e. to drink enough) by drinking at least six glasses of water a day. If you are feeling tired, avoid consuming drinks containing caffeine, such as coffee or energy drinks, to try to wake you up, as they may stop you from sleeping later.

If you are struggling with your daily food intake to the point where it is affecting your weight, it may be helpful to speak to a dietitian (or ask to be referred to one through your doctor). Make sure to brush your teeth twice a day.

#### Smell and/or taste problems

If you are experiencing reduced smell or taste, you can try the following:

- ▶ experiment with the temperature of your food and drinks, as this affects the taste hot dishes have a stronger taste than (ice) cold ones; find the temperature at which dishes taste best to you, for example directly from the fridge, at room temperature, very hot or slightly cooled;
- when experiencing altered taste, chew thoroughly and let food spread through your mouth before swallowing to maximize the flavour; and
- ▶ perform smell training, which involves sniffing lemon, rose, garlic and eucalyptus for 20 seconds each, twice a day.

#### **Managing pain**

Pain is a common symptom in long COVID. It can affect specific regions of the body (joint pain, muscle pain, headaches, chest pain and stomach pain) or be widespread. Pain can be disabling and can affect your sleep, fatigue levels, mood and ability to focus.

If you experience specific pain symptoms, such as chest pain, that get worse during activity, you should contact a health professional.

#### Advice on managing pain

- ► For joint, muscle or widespread pain, painkillers such as paracetamol can be helpful. Discuss this with your trusted adult and/or a health professional.
- ➤ Some discomfort or pain can be acceptable, which means that, even though you may feel mild pain, you are still able to take part in activities you like to do. However, be careful not to push yourself too hard, as it can make the pain and symptoms worse later on.
- ▶ Pacing yourself in daily activities is one of the key tools for managing your pain, as (light) activity can help to release hormones called endorphins which can relieve pain.
- ▶ Sleeping well can help to reduce pain symptoms.
- Listening to relaxing music or meditating can also help to reduce pain levels.
- ▶ If you are struggling with activities of daily life, you may find that generally moving the body can help to reduce pain. Slowly and gently moving your limbs through their natural range of movement (being careful not to push through pain) or stretching can be helpful. This activity can be spaced out through the day.
- ▶ If you are having trouble managing pain yourself, or if it is interfering with your daily activities, you should seek help from a medical professional. It is important to inform your health professional if you are experiencing PESE.

### Education

Returning to learning can be challenging when you have long COVID. Talk to your trusted adult as well as your teachers and other professionals at school so they can help with a flexible plan for attending your school or education setting as much as you can.

#### What can I do?

- ▶ Make a plan that does not use all your available energy for school, but also leaves spare energy for activities you find fun and enjoyable. Discuss with your contact person from school a return-to-school plan that gradually increases your workload and hours at school as your symptoms and pacing allow.
- ▶ Review the plan regularly to ensure it supports your health and avoids further absences from school as far as possible.
- ▶ Make sure that your symptoms are stable and manageable for 2-3 weeks before you try to increase your workload, even by a small amount. The symptoms of long COVID can fluctuate, so it is important for you to allow time to establish your baseline.
- ▶ Your study pattern can be adjusted as necessary, for instance through:
  - · altered start and finish times
  - · studying from home
  - · taking less demanding courses or classes.
- ▶ Discuss with your teacher how your homework load can be adjusted.
- ➤ Your contact person can also refer you to the school nurse, counsellor, educational psychologist or other school-based therapist, who can give you further advice and support.

Don't be afraid to step back if you have gone too quickly, and don't add extra workload or hours if your symptoms are worsening. It is better to maintain a lower level of activity for longer than to push too hard and experience a worsening of symptoms. It isn't unusual to spend several weeks at one level of activity before making a small increase and then monitoring symptoms, then adding in more activities/more hours at school or study if symptoms are stable.

#### **Exams**

Exams and coursework are an important part of education, and you may be worried about how you will manage them. There are many ways to study; it is helpful to discuss them with your trusted adult or the contact person from your school. If you have missed lots of your education, there may be additional support you can access, or you may need to consider reducing the number of subjects you study for now.

Tips for studying for exams:

- ▶ be realistic if you plan too much, you may put yourself under unnecessary stress; and
- practise pacing, including regular breaks from studying.

In some situations, schools can offer special arrangements for exams. These may include later start times, rest breaks during the exams, extra time or even a scribe or reader to support you. It can be helpful to discuss options with your school contact person at an early stage, as these arrangements may take some time to put in place.

## Activity tracker<sup>1</sup>

Mark each hour block with the colour that corresponds to your activity level: sleep, rest, low-energy or high-energy activity. If you are experiencing post-exertional symptom exacerbation/extreme fatigue (crash), mark with an X.

High-energy activity (physically, mentally or emotionally demanding)

■ Rest ■ Sleep

Low- or medium-energy activity	(less demanding)
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Activity tracker																									
	Midnight to midday (morning)													N (a	1id Ifte	day	/ to	m n/e	idr ve	nigl nin	ht g)		Symptom notes		
Date	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11	
Monday																									
Tuesday																									
Wednesday																									
Thursday																									
Friday																									
Saturday																									
Sunday																									

X: post-exertional symptom exacerbation/extreme fatigue (crash).

Adapted from the World Physiotherapy Activity Diary. London, UK: World Physiotherapy; 2021 Available from: https://world.physio/sites/default/files/2021-06/WPTD2021-ActivityTracker-Final-v1.pdf

## Handout to help others to understand long COVID

#### What is long COVID?

The combination of symptoms I have is called long COVID. My symptoms have a significant impact on my life. Everyone will have their own experience of long COVID. This is to help you understand more about how it may affect me.

#### How my condition may affect me

Below are some common symptoms which may have a big impact on my life.

- ► Fatigue: exhaustion which is different from the normal tiredness that healthy people experience. This fatigue is usually not relieved by rest and can be worse after activity.
- ▶ Post-exertional symptom exacerbation: symptoms worsening after activities or exercise.
- ▶ Pain: pain can occur anywhere. Headaches and intense muscle and joint pain are common.
- ▶ **Difficulties with thinking**: difficulties with memory, concentration, word finding and planning. These symptoms are commonly called "brain fog".
- ▶ Other symptoms: body temperature disturbance, dizziness, sensitivity to light and noise, sleep disturbance, nausea, loss of appetite and/or smell, gastrointestinal disturbances and sensitivity to food and medication.

My main symptoms are:

#### How you can help me

It helps when other people understand my condition, are supportive and ask what help I need, as my symptoms can change from day to day, even if I look well.

On good days, I should be encouraged not to "push through" or do too much, even if I am feeling better than usual. Doing too much can lead to more fatigue, pain and feeling worse on the following days. On a bad day, I may need some flexibility. Balancing activity and rest ("pacing") can help me to manage my symptoms better and keep my energy levels more consistent.

At first, I may need help in planning how much I can manage. This may mean reducing my school timetable for some time and prioritizing my health. I may need more support in school than I used to, and my attendance may be intermittent, even when I am trying my best.

The things that help me:	
The things that I don't find helpful:	

You can find out more about my condition here: https://iris.who.int/handle/10665/373025.

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