

## PATIENT INFORMATION

# ME/CFS (Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome) Managing Flare ups

### Flare ups/Setbacks and Relapses

Flare ups/setbacks and relapses can happen in ME/CFS, Long Covid and fibromyalgia even if the person's symptoms are well managed.

Flare up/setback:

- The worsening of symptoms – more than the day-to-day current variation.
- Could be in line with post exertional malaise/post exertional symptom exacerbation.
- Usually lasts for a few days – may require temporary changes/pairing back to activities and routines for a few days

Relapse:

- Lasts longer (weeks or months) – may require substantial and sustained adjustment to activities and routines

It may not be clear if it is flare up or relapse initially.

### Triggers

Sometimes symptoms seem to flare up 'out of the blue', but often we can identify triggers that may have contributed to a flare up/setback/relapse.

For example:

- If you get another illness
- If there are new stresses or tensions – a disagreement or a particular worry
- Major life events like moving house or changing jobs; sometimes they may be pleasant events such as a wedding or holiday
- Changes in your routine such holidays, changes in weather or clocks
- Increase in activity levels such as returning to work
- Increased pressures such as exams or work deadlines

All of the above can impact on our ability to pace, plan and prioritise.

**Guidance to manage flare ups/setbacks and relapses:**

- Reduce or pair back activity levels. This may be a temporary reduction for a flareup/set back. It may need to be a more substantial and sustained reduction for a relapse.
- If you are resting more, continue to keep up with gentle movement and stretching. This helps to improve circulation and encourages muscles to relax. It also will help to maintain mobility
- Do not assume a change or new symptoms are caused by the condition and seek advice from GP or specialist.
- Do not return to usual activity levels until the flare up has resolved – consider using a graded approach.

Please remember a flare up/setback or relapse does not mean that you are back at square one.

### **Flare up/setback/relapse management plan**

It can be hard to know what to do when you are in the middle of a flare up/setback or relapse. People have found it helpful to have a management plan like this to hand to refer to.

1. What factors/triggers may have contributed to a flare up/setback/relapse in my condition?

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- .....
- .....

2. What are the early signs/symptoms and impact on daily life for you that may indicate a possible flare up/setback/relapse?

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3. What things have been helpful for me when I've been in a flare up/setback/relapse in the past?

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**Supporters.**

List the people who can provide you with additional support and might need to be contacted. They can be family members, friends, healthcare professionals or your care coordinator. You may want to name some people for certain tasks.

These are my supporters:

E.g. Name John Smith Phone No. 01777 7654321	Connection Neighbour, has spare key will feed cat and water plants
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Name..... Connection.....

Phone No.....

Name..... Connection.....

Phone No.....

For further assistance or to receive this information in a different format, please contact the department which created this leaflet.