

**URBAN
SAINTS**

RESOURCE



Chronic Fatigue Syndrome / ME

Effective support for young
people with additional needs

Chronic Fatigue Syndrome / ME

Chronic Fatigue Syndrome (CFS) or ME (myalgic encephalopathy or encephalomyelitis) is a complex multisystem condition with a wide range of disabling symptoms.

ME in most cases is believed to be triggered by a known event such as an acute infection, a problem with the immune system, or a hormonal imbalance. People with ME often report that they don't feel as though they have recovered from the symptoms even after e.g. *the infection has passed*. In some cases, ME can develop following different triggers.

Most people with ME will make some degree of improvement over time, especially young people. However, a significant minority remain permanently and severely affected and many will see fluctuations in severity over a period, with some getting progressively worse.

ME can also affect mental and emotional health and have a negative effect on self-esteem.



Key issues

- Periods of overwhelming tiredness or malaise, which can last for days or even weeks.
- Problems with cognitive functions such as short-term memory, concentration, word-finding.
- Sleeping too little or too much, vivid dreams, feeling unrefreshed by sleep.
- Ongoing flu-like symptoms including sore throat, feeling lethargic.
- Can have problems with pulse and blood pressure, leading to feeling faint or dizzy.
- May experience pain, especially in muscle joints and nerves.
- Can be sensitive to bright light or loud noise.



Support strategies for your group

- **Believe a young person when they say they have CFS/ME;** this is important as recognising this condition as real has not always been the case for many with ME.
- **Ensure the right balance** between activities and rest. This is known as 'pacing' or 'energy management'.
- **Find roles/ways to be involved** in games or activities that are less physically demanding e.g. 'scorer', 'referee' etc.
- **Let young people communicate** when they need to stop and rest and give them space to do this.
- **Some young people may take medication** to help control their CFS/ME.
- **Mental health and safeguarding**
Be alert to the possible impact on mental health and self-esteem and offer positive affirmation and opportunity to talk. If you are concerned about the young person's mental health discuss this with your groups safeguarding lead.



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Thanks to **ME Association** for much of the material used in writing this article.

Further Information: The ME Association: meassociation.org.uk

Research shows that young people with additional needs are more likely to be abused than their peers (NSPCC) This increased vulnerability is due to a number of factors including communication differences, increased dependence on caregivers, social isolation and a higher likelihood that warning signs would be missed or misinterpreted. As a youth leader it's therefore important to be especially alert to changes in behaviour and wellbeing and discuss any concerns with a safeguarding lead at the earliest opportunity.



**This resource is just one
of the many ways we're
here to walk with you!**

Discover more free tools, training
and resources to equip you in
disciplining young people.

urbansaints.org

This resource has been adapted from our Invited to Belong Team Training Kit.



If you're interested in helping your team become more aware and welcoming of young people with additional needs, you can explore our Invited to Belong Team Training Kit at urbansaints.org/resources

The original content of this resource was created in partnership with **Youthscape** as part of the Invited to Belong resource.