

Symptoms

Contact Us

About Educational Health Care Plans (EHCP)

Autoinflammatory conditions are not to be confused with Autoimmune conditions such as Rheumatoid Arthritis or Crohn's Disease. Autoinflammatory conditions are rare and complex mainly caused by changes in genes. Autoinflammatory conditions are associated with the innate immune system, whereas Autoimmune conditions are associated with the adaptive immune response.

- Fevers
- Rigours (shakes with fevers)
- Sore Throats
- Gastrointestinal Issues
- Enlarged Spleen and Liver
- Genital Ulcers
- Inflammation of the joints and skin
- Uveitis (inflammation in the eyes)
- Respiratory Issues
- Headaches
- High C - Reactive Protein (CRP)
- Enlarged Lymph Nodes (Glands)
- Constipation
- Nausea
- Diarrhoea
- Rashes
- Anaemia



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Rare Autoinflammatory
Conditions Community - UK
(RACC - UK)

Parent / Carer Involvement

Things to remember

Organisations to help

You as parent/carers should be involved with your child's EHCP. As you know your child best, you will be the best advocate for your child's needs.

The process in writing an EHCP can feel long and at points frustrating. However, everyone involved is working to achieve the best outcome for your child.

Through the process there will be different case meetings; these can be in school, nursery, hospital or sometimes your home. These are to create an easy to use document for everyone.

If at any stage you have any thoughts, concerns or questions, make sure you're voicing them. Also, if your child is able, then they will be asked for their opinion on proceedings.

Each year you and your child (if appropriate) will be invited to an Annual Review. This will be a meeting to update any targets or plans that your child needs. If there are any changes throughout the year, then the plans can still be updated. At these meeting all professionals can also discuss any additional referrals that the child may need.

Your child's nursery or school staff may not have previous experience with students with autoinflammatory conditions.

Topics that they need to understand, and which may need to be written into a formal EHCP, include:

(a) your child will probably sometimes be too unwell to attend school, and their incomplete attendance record must not lead to any disadvantage for them (e.g. celebrations for children with full attendance). Teachers should provide take-home work or make provisions for the child to catch up on missed learning so that their unavoidable absences do not damage their education. A reduced timetable may be beneficial.

(b) if your child is unwell because of their condition, possibly with a very high temperature, they are not infectious. If they feel well enough to be in school, they must be allowed to attend school.

(c) your child may need special provision to rest during the school day or sit out of energetic activities if they feel unwell, and all school staff must be aware of this.

Children with special educational needs and disabilities (SEND)

Individual Health Care Plan.pdf

Education, Health and Care plans | (IPSEA) Independent Provider of Special Education Advice (<https://www.ipsea.org.uk/>).

How to apply

You as parents / carers, schools or other professionals involved in your child's care can apply for an EHCP through your local authority. For example, [Special educational needs and disability: The local offer | Oxfordshire County Council](#)