Clinical Guidance

Guide for clinicians commencing steroids in a child with epilepsy

Summary

The main indications for steroids in children with epilepsy are infantile spasms, epileptic encephalopathy, electrical status epilepticus in slow wave sleep (ESES), immune-related epilepsy, and drug-resistant epilepsy. This is a guideline to outline the considerations prior to commencing, monitoring of these patients and advice that needs to be given to parents.

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A recent review of steroid use in children with epilepsy in ELCH showed that most of children starting steroids with epilepsy were under the age of 2 years, and the majority had infantile/epileptic spasms. The main things to consider in this age range are changes to the routine vaccination schedule and susceptibility to chicken pox.

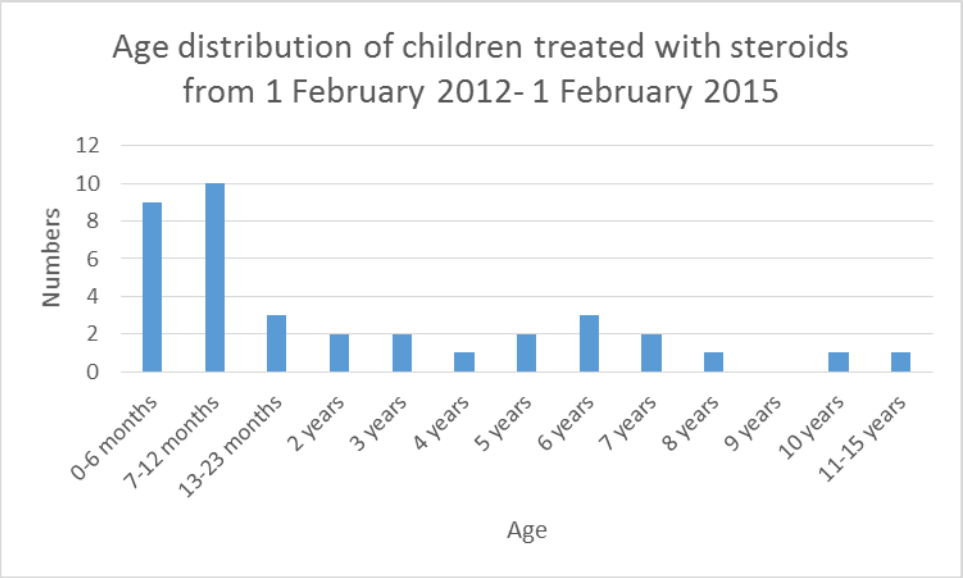


Table 1. Age distribution of children treated with steroids in ECH, Feb 2012- 2015

There are potential significant side effects of steroids treatment including hypertension, hyperglycaemia and glucose intolerance; electrolyte disturbances, immunosuppression, Cushing syndrome, weight gain, behavioural difficulties, irritability, cardiac hypertrophy, osteoporosis, and cerebral atrophy.

Immunosuppression from steroids occurs when doses of 2mg/kg/day or 40 mg once a day of prednisolone (or equivalent, for other steroids) for longer than 1 week, or 1mg/kg for 4 weeks or longer are administered. The effects of immunosuppression can last up to 3 months after discontinuation of steroid therapy (Gupta and Appleton 2005, BNFc, 2014).

It cannot be assumed that infants treated with steroids will be protected from developing chickenpox by protection from maternally derived antibodies. Maternally derived passive immunity is considered to be present in infants until the age of 6-9 months, and antibodies levels usually have declined by the age of 8 months. However, not all infants of this age or younger will still have passive immunity. There is evidence suggesting that in pre-term infants maternally derived antibodies have declined by the age of 3 months.
Enquiring if the child has had chickenpox is imperative, but it is also essential to question if there has been any known recent contact with chickenpox, prior to initiating treatment with steroids. Chickenpox has an incubation period of 10-21 days; it spreads by droplet infection 1-2 days before the appearance of the rash and by direct contact, for 5-7 days once the rash is apparent (Vyse et al., 2004, Heininger and Seward, 2006, Kempf et al., 2007, Viner, 2012). It is

highly contagious; up to 96% of non-immune contacts of a person with chickenpox develop the disease (Heininger and Seward, 2006).

Checklist

Things to consider before starting steroids:

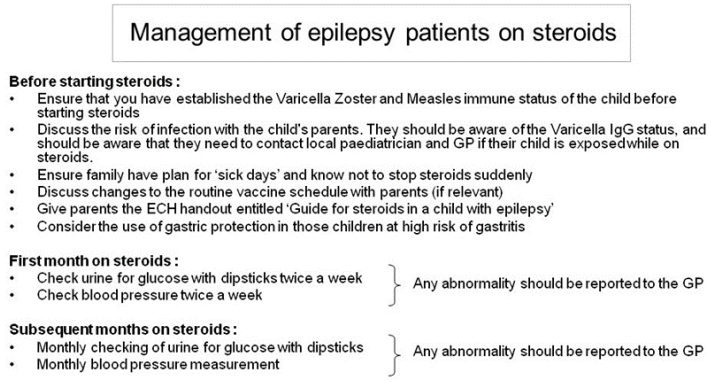
- ☐ Give parents information sheet regarding steroid use in Epilepsy, and steroid card. https://bnf.nice.org.uk/drug/prednisone.html
- ☐ Discuss side-effects of steroid therapy in particular in the short term weight gain, behavioural changes, sleep disturbance, hypertension, glycosuria/ diabetes, infection (emphasising the need to seek medical attention if exposed to chickenpox) , and if used in the longer term, the risk of height restriction, cataracts, osteoporosis and fracture.
- ☐ The following tests are recommended prior to commencing treatment with steroids:
    - Full blood count/Liver profile/ Renal profile/ Bone profile/Vitamin D level
    - Random glucose/urinalysis (fasting if elevated)
    - Varicella zoster and measles serology
    - Baseline blood pressure
- ☐ Document immune status for varicella zoster and measles. If serum IgG is negative for varicella- zoster antibodies recommend vaccination if treatment with steroids is planned more than three months in the future. The varicella- zoster vaccine is a live vaccine, requiring 2 doses 4-8 weeks apart, and it is a further 2-4 weeks before steroid therapy can be commenced. Vaccination is not an option in the case of infantile spasms as treatment must start immediately.
- ☐ If there is contact history of tuberculosis, seek paediatric infectious disease advice before commencing treatment
- ☐ If random glucose is elevated check fasting glucose and if necessary glucose tolerance test prior to starting steroids

Things to consider while on steroids:

- ☐ Write to GP to request prescription for steroid and for urinalysis testing sticks to monitor for urine glucose.
- ☐ Set up home monitoring for blood pressure (community nurse) and urine glucose (usually by family being provided with dipsticks): twice a week for the first month, and if steroids continue and then once per month thereafter. If urine glucose positive, family should contact GP who should check random blood glucose and if elevated should check fasting glucose/ glucose tolerance test. Home monitoring is usually organised through community nursing.
- ☐ Routine vaccination schedule for children under 2 years: Children should have all non-live vaccinations but this should be discussed with parents, by prescribing paediatrician prior to starting steroids. Advise parents that children on steroids **cannot have live vaccinations** when on steroids or within 3 months of stopping. Rotavirus, MMR and varicella vaccines are all live vaccines.
- ☐ Consider use of ranitidine or proton pump inhibitor for duration of steroids therapy if no contraindications
- ☐ Chickenpox and measles exposure: Parents should be advised to avoid exposing their child (and other children in the family) to other children with chickenpox, measles or influenza for the course of steroids,

and three months afterwards. If the child on steroids (or within three months of stopping steroids) is exposed to chickenpox, and has not previously had chickenpox (or is IgG negative) the parents should be aware that they must contact their local paediatrician or GP immediately. The local team will decide if the child should get Varicella Zoster Immunoglobulin (VZIG) or acyclovir. This needs to be as soon as possible, preferably within 72 hours of exposure, but no later than 7-10 days after exposure. This is prophylaxis only.

- ☐ For children who contract chickenpox for the first time while on steroids, hospitalisation and intravenous (IV) aciclovir is recommended.
- ☐ If a child is on steroids but has had chickenpox before (confirmed IgG positive) and is exposed to chickenpox, they do not need prophylaxis as their chances of getting it again are very small. However if they do develop symptoms of chickenpox parents must discuss this with your paediatrician immediately.
- ☐ [It is best to discuss individual cases with local PID team. Guidelines for medical practitioners on management of chickenpox while on steroids are available in The Green Book; Chapter 34 http://allcatsrgrey.org.uk/wp/wpfb-file/green_book_chapter_34_patch_v3_0-pdf/
- ☐ Parents should be aware of sick day rules if their child is on high dose steroids – this should be discussed with the local team
- ☐ Ensuring that parents are aware that steroids cannot be stopped suddenly.
- ☐ If a decision has been taken to discontinue steroid treatment after a long course of treatment then a short synacthen test could be arranged within 48 hours of discontinuation. The paediatric endocrine team at Evelina London have a specialist nurse who can perform adrenal axis suppression testing if required.
- ☐ If steroids are used long term should consider further follow up for bone health/DXA scan/vitamin D, monitoring for cataracts, and growth parameters
- ☐ If the child is on doses greater than 20mg/m2 and generally greater than 2 weeks then the endocrine team recommends that the child should have adrenal insufficiency training. The concern is that if they have a stress event they cannot mount an adequate response. The endocrine CNS takes referrals for a one off training sessions for families and if they are still on steroids after a year, they will do an update.



Advice to parents/guardians of children with epilepsy who are on steroids

Your child has been started on steroids for management of epilepsy. It is very important that doses of this medicine should not be missed and must not be stopped suddenly, as this can be very problematic.

Side affects you need to know about are:

- **Weight Gain**: Your child is likely to feel hungrier. Try not to give them sweet or fatty snacks. It is better to fill up with extra fruit and vegetables.
- **Behavioural changes**. Your child may seem irritable especially when they are first taking the tablets/injections. This should settle down over time but please let us know if it is a big problem.

- **Raised blood pressure**. The community nurses will check your child's blood pressure twice a week for the first 4 weeks of treatment then monthly.
- **Raised blood glucose level**. You should test your child's urine for sugar twice a week for the first week of treatment then weekly. Let us or your GP know if it is positive
- **Stomach irritation.** Your child is likely to have been started on a medication to help prevent stomach irritation. If your child is not on this and gets tummy pain let us know as we can prescribe the medication to help with this. It's important to get medical help if your child seems to be complaining a lot of having tummy ache. You should avoid giving your child ibuprofen as this can also irritate the stomach.
- **Delayed healing.** Wounds may take a bit longer than usual to heal.
- **Increased susceptibility to infection.** The infections we worry about are chicken pox and measles. If your child comes into contact with chicken pox or measles you should contact the local paediatrician or GP immediately.
- If your child has not had chickenpox before the doctor may decide to give a medication to help prevent the severity of chicken pox should it develop. If your child develops chickenpox while on steroids, it is likely they will have to go to hospital to have an intravenous medicine (see below).
- If your child has not been vaccinated and comes into contact with a child with measles you must call your local paediatrician or GP straight away.

Longer term side effects.

- **Thinner bones**. Having good levels of vitamin D will help prevent this.
- **Cataracts**. Only a problem after a long time on steroids. Children with epilepsy are usually only on steroids for a short period of time.

Vaccination advice

- Your child can still have non-live vaccinations, but discuss with your paediatrician prior to doing this
- Live vaccinations (Rota virus, MMR and Varicella) should be delayed for three months after stopping steroids

Exposure to chicken pox

Chickenpox can be a very serious illness in children on steroids, and therefore it is recommended that you avoid exposing them to other children with chicken pox if at all possible. If your child is exposed to someone with chicken pox (or a child who is about to develop chicken pox), and has not previously had chicken pox or did not show immunity to chicken pox on testing, then you should contact your local paediatrician or GP immediately. Chickenpox symptoms may not appear until 21 days after your child has been exposed to it. Your paediatrician will decide if your child should get a Varicella Zoster Immunoglobulin (VZIG) injection or aciclovir. This needs to be as soon as possible, preferably within 72 hours of exposure, but no later than 7-10 days after exposure. This is prophylaxis only.
For children who get chickenpox for the first time while on steroids, intravenous (IV) aciclovir is recommended.

If your child is on steroids but has had chickenpox before (and has demonstrated immunity on testing) and is exposed to chicken pox then they do not need prophylaxis as their chances of getting it again are very small. However if they do develop symptoms of chicken pox you must discuss this with your paediatrician immediately.

Exposure to measles

If your child has been exposed to measles infection you must inform your local team.

Sick day rules

If your child has been on steroids for a long time and becomes ill they may need an increase in steroids dose, speak to your doctor about this.

Axis suppression

If a child has been on a steroids at a high dose for a long time they may require adrenal axis testing prior to weaning off steroids. This can be discussed with your doctor. The Endocrine team in the Evelina have a specialist nurse who can arrange this testing if needed.