

ESSENTIAL POINTS TO REMEMBER IF YOUR CHILD IS GOING TO TAKE DEFLAZACORT™

1. Do not change the dose without checking with your child's doctor. The dose was calculated by your child's weight. Sometimes your child's doctor may increase the dose - if your child has grown a lot and not developed side effects. Sometimes the doctor may decrease the dose - if side effects develop.
2. Your child should take the complete daily dose at one time in the morning after breakfast. This helps to reduce stomach upsets, and may minimize weight gain and other potential side effects.
3. If your child forgets a dose, he should take it as soon as possible unless it is almost time to take the next scheduled dose. If this is the case - do NOT double up on the dose. Skip the missed dose and continue with the regular schedule. If two or more doses are missed, call your child's doctor for assistance.
4. If your child gets sick and is vomiting, contact a doctor. (This can be your family doctor, paediatrician or the neurologist). If he is SICK and can't take the *Deflazacort™*, he may need it replaced by injection.
5. Inform all caregivers that your child is on steroids. Your child should wear a Medic Alert™ bracelet. This should state that he has Duchenne Muscular Dystrophy and is taking a steroid. If he is sick or has an accident, this will let the attending doctor know about his disorder and the need for intravenous steroids.
6. For more information about MedicAlert™, contact MedicAlert™ Canada at 1-800-668-1507 or check their website at www.medicalert.ca.
7. If your child has not had chickenpox or has not had an immunization shot for chickenpox, we strongly recommend being vaccinated 3 months before starting treatment with *Deflazacort™*. If your child gets chickenpox while on *Deflazacort™*, it can lead to complications.

Normally, the adrenal glands make steroids. Steroids help during infection, times of stress, or after an accident. If your child takes steroids by mouth, his own adrenal glands stop making the natural steroid and the body has difficulty

reacting to stressful events to produce more steroids. This can cause a drop in blood pressure. If this becomes very low the body can go into "shock". This can be prevented by replacing with further steroids which may need to be given by injection while he is ill.

If your child is on steroids and has not had chickenpox or been vaccinated and is exposed to it (been in contact with other children who have chickenpox), you should call a doctor. A general guideline is to give an immunization shot (Immune Globulin (Zoster)) within 72 hours after exposure to the person who has

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chickenpox. If you/your doctor have any questions, contact the Neurologist on call at BCCH, at phone number (604) 875-2161.

8. It is safe to have the vaccinations for the flu, hepatitis and meningococcus while on steroids. If possible, the vaccinations should be given at least 3 months prior to starting *Deflazacort™* to ensure enough protection.
9. If you want your child to stop taking *Deflazacort™*, **he must so under the guidance of a doctor.** The dose has to be lowered gradually over several weeks or months. This will allow your child's adrenal glands time to start making the steroid again.
10. In order to watch for side effects, your child must be seen by his General Physician (GP) or Paediatrician and the Neuromuscular Clinic Team regularly while taking *Deflazacort™*. At these regular appointments, your child's weight, height, and blood pressure will be monitored. He will have his urine tested for sugar and his eyes examined for cataracts. This must be done one month after starting *Deflazacort™* and then every 3 months while he is on *Deflazacort™* therapy.
11. To attempt to minimize the development of osteoporosis while on steroids, we give extra calcium and vitamin D. We suggest 1000 mg calcium per day and 1000 IU vitamin D per day.

12. Weight gain is a potential side effect of steroids. We recommend that you prepare foods that are low in fat and high in nutritional value. We also recommend foods that are low in salt. If you have concerns, ask to see a nutritionist to help you with your child's diet plan.

Developed by the health care professionals of the Neuromuscular Clinic with assistance from the Department of Learning & Development.

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