

## Side Effects of Long Term High-Dose Steroid Therapy

| Steroid side effect                                      | Monitor   | Potential treatment options  |
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| <b>Weight gain and obesity</b>                           | <p>Dietary advice should be provided to families before starting a steroid regimen to avoid weight gain</p> <p>Steroids often increase your appetite</p>  | <p>It is important that the whole family eat sensibly in order to prevent excess weight gain. Healthy eating plans can be found at <a href="https://www.choosemyplate.gov">https://www.choosemyplate.gov</a></p>   |
| <b>Cushingoid features (“moon face”)</b>                 | <p>You may notice fullness in the face and cheeks becomes more noticeable over time</p>   | <p>Maintaining a healthy diet and minimizing sugar and junk food can help minimize these features</p> <p>It may be advised by a doctor to restrict salt intake</p>   |
| <b>Excessive growth of hair on the body (hirsutism)</b>  | <p>You or your child may notice more hair on the body</p>   | <p>This is not usually severe enough to warrant a change in medication</p>   |
| <b>Acne, fungal infections of the skin(tinea), warts</b> | <p>More noticeable in teenagers</p>   | <p>Use specific treatments (topical prescription) and do not rush to change the steroid regimen unless there is emotional distress</p>   |
| <b>Short stature</b>                                     | <p>Ensure height is measured every 6 months as part of general care to track growth</p>   | <p>If you feel growth has slowed or stopped, discuss with your neuromuscular specialist, they may refer you to an endocrinologist</p>  |
| <b>Delayed puberty</b>                                   | <p>Monitor your pubertal development at home</p> <p>Identify any family history of delayed sexual maturation (i.e. explore ages parents went through pubertal changes)</p>                      | <p>If you or your child are concerned about his pubertal development or if puberty has not started by age 14, ask your neuromuscular specialist for an endocrine evaluation</p> <p>Testosterone replacement therapy is generally recommended for boys who have not started puberty by age 14</p>                               |
| <b>Adverse behavioral changes</b>                        | <p>Identify any baseline mood, temperament, and ADHD issues (even before starting steroids)</p> <p>Be aware that these often temporarily worsen in the initial six weeks on steroid therapy</p> | <p>Baseline behavior issues should be treated prior to starting steroid therapy, e.g. ADHD counseling or prescription</p> <p>It may help to change the timing of steroid medication to later in the day (avoiding the school/work day) - discuss this with your doctor, who may also consider a behavioral health referral</p> |
| <b>Immune suppression</b>                                | <p>Taking steroids can reduce immunity (the ability to fight infections). Be aware of risk of serious infection and the need to promptly address minor infections</p>                           | <p>Avoid “live” vaccinations if possible or talk to your primary care doctor about getting them before you start steroids</p>  |

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| <p><b>Adrenal suppression</b></p> <p><b>*This is a potential life-threatening medical emergency that can happen if steroids are stopped suddenly and the body produces insufficient levels of cortisol, or “stress hormone”</b></p> | <p>If you need to go to a new doctor, an emergency room, or urgent care, let them know you are on steroids, and carry a steroid alert card</p> <p>It is very important that steroids doses are not missed for more than 24 hours for any reason</p> <p>Know when stress dose steroids should be given (severe illness, major trauma or surgery) to prevent adrenal crisis</p> <p>Know the signs and symptoms of adrenal crisis (stomach pain, vomiting, lethargy)</p> <p>Have a vial/kit containing hydrocortisone for intramuscular injection at home and know how to administer in case of adrenal crisis (prescribed by a NMS)</p> | <p>Ask your doctor for a “Stress Dose Steroid Plan” that explains:</p> <ul style="list-style-type: none"> <li>• What to do in the case of a missed steroid dose &gt;24 hours (because of fasting, illness, or prescription unavailability)</li> <li>• When to give stress dose steroids, at what dose, and in what form (by mouth, by intramuscular injection or by IV); consult the “PJ Nicholoff Steroid Protocol” for an example plan: <a href="http://www.parentprojectmd.org/site/DocServer/PJ_Nicholoff_Steroid_Protocol.pdf?docID=15843">http://www.parentprojectmd.org/site/DocServer/PJ_Nicholoff_Steroid_Protocol.pdf?docID=15843</a></li> <li>• If your child is going to stop taking steroid medications, ask your doctor for tapering plan. They can refer to the PPMD “PJ Nicholoff Steroid Protocol” for an example plan: <a href="http://www.parentprojectmd.org/site/DocServer/PJ_Nicholoff_Steroid_Protocol.pdf?docID=15843">http://www.parentprojectmd.org/site/DocServer/PJ_Nicholoff_Steroid_Protocol.pdf?docID=15843</a></li> </ul> |
| <p><b>Hypertension</b></p>  | <p>Monitor blood pressure (BP) at each clinic visit</p>   | <p>If BP is elevated, reducing salt intake and weight reduction may be useful first steps (under supervision of your cardiologist)</p> <p>Your cardiologist may prescribe blood pressure medication</p>   |
| <p><b>Glucose intolerance (high blood glucose levels)</b></p>   | <p>Test urine for glucose with dipstick test at clinic visits</p> <p>Inquire about increased urination or increased thirst</p> <p>Blood test once a year to monitor for development of type II diabetes and other complications of steroid induced weight gain</p>  | <p>Further blood tests may be needed if urine tests or symptoms are positive</p>  |
| <p><b>Gastritis/ gastroesophageal reflux</b></p>  | <p>Look out for reflux symptoms (heartburn)</p>   | <p>Avoid non-steroidal anti-inflammatory drugs (NSAIDs) - such as aspirin, ibuprofen, naproxen</p> <p>Antacid can be used for symptoms</p>  |
| <p><b>Peptic Ulcer Disease</b></p>  | <p>Report symptoms of stomach pain as this can be a sign of damage to the lining of the stomach</p> <p>Stool can be checked for blood if anemic or if there is suggestive history</p>   | <p>Avoid NSAIDs (aspirin, ibuprofen, naproxen)</p> <p>Drugs and antacid can be used if symptomatic</p> <p>Seek gastrointestinal consultation</p>  |

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| <p><b>Cataracts</b></p>   | <p>Annual eye exam to look for cataracts</p>  | <p>Consider switching from deflazacort to prednisone if cataracts evolve that affect vision</p> <p>Seek ophthalmology consultation</p> <p>Cataracts will only need to be treated if they interfere with vision</p>  |
| <p><b>Osteoporosis</b></p>  | <p>Take careful fracture history and ask about back pain at all visits</p> <p>Spine x-rays every 1-2 years to monitor for vertebral compression</p> <p>DEXA every 2-3 years to monitor bone density</p> <p>Yearly vitamin D blood level (ideally late winter in seasonal climates) and supplement with vitamin D3 if levels are low</p> <p>Yearly assessment of calcium intake by a dietician</p> | <p>Vitamin D supplements may be needed depending on level in blood</p> <p>Check 25 OH vitamin D levels annually; supplement as needed.</p> <p>Make sure that dietary calcium intake meets recommendations for age</p> <p>Calcium supplements may be needed if unable to meet</p> <p>Weight-bearing activities can be helpful for bone health</p> <p>Discuss with your NMS/PT before starting an exercise/weight bearing program</p> |
| <p><b>Myoglobinuria</b><br/>(Urine looks reddish-brown colored because it contains breakdown products of muscle proteins. This needs to be tested for in a hospital lab.)</p> | <p>Report any reddish-brown urine to your child's doctor</p> <p>Urine can be tested for myoglobin</p>   | <p>Avoid vigorous exercise and eccentric exercises, such as running downhill or jumping on a trampoline</p> <p>Good fluid intake is important</p> <p>Kidney exams and tests are needed if it persists</p>   |