

Common Physical Health Challenges in the Aging Adult with Prader-Willi Syndrome

Health Concern	Risk Factors in PWS	Screening/ Monitoring	Prevention & Management Suggestions	Comments
Obesity	<ul style="list-style-type: none"> • Strong food seeking behavior • Family history • Low thyroid • Low activity levels 	<ul style="list-style-type: none"> • Daily weight monitoring • Thyroid testing • Blood lipid monitoring 	<ul style="list-style-type: none"> • Low calorie/ high nutritional diet • Food security • Exercise 	<p>Obesity impacts almost all aspects of our health. Contributes to:</p> <ul style="list-style-type: none"> • Breathing/respiratory problems • Bone degenerative changes & mobility issues • Circulation / vascular issues • Diabetes • Bowel / Intestinal issues
Respiratory Insufficiency	<ul style="list-style-type: none"> • Spine deformities • Sleep apnea • Poor muscle tone • Low activity levels • Other Health problems – asthma, allergies, heart disease • Smoking 	<ul style="list-style-type: none"> • X-rays of spine • Sleep Studies • Pulmonary function testing • Oxygen levels • Monitoring of chronic health issues 	<ul style="list-style-type: none"> • Early intervention and treatment of spine deformities • Encourage good posture • Oxygen therapy • Diagnosis and treatment of sleep apnea • Prompt evaluation & treatment of lung infections & chronic lung conditions • Keep moving • Annual influenza & pneumonia vaccines • Sleeping upright may assist in breathing • Smoking Cessation measures 	<p>Major cause of death in adults with PWS.</p> <p>Sleep apnea is often a significant risk factor for those undergoing any surgical procedure requiring general anesthesia.</p>
Low Bone Density, Degenerative Changes and Mobility Issues	<ul style="list-style-type: none"> • Decrease in hormone production – GH, estrogen, testosterone • Arthritic changes • Vitamin & Mineral deficiencies –Vit. D, Calcium • Poor Muscle tone • Vision changes • Medications 	<ul style="list-style-type: none"> • Hormone level testing -GH, sex hormone, thyroid function levels. • Bone density testing – DEXA scan • Vitamin & mineral level monitoring – calcium, phosphorous, magnesium, parathyroid hormone, alkaline phosphatase, serum 25 Vitamin D • Annual eye exams 	<ul style="list-style-type: none"> • Hormone replacement • Bone density monitoring • Treatment of documented osteoporosis • Vitamin & mineral replacement and/or supplementation • Dietary consultation on nutritional ways to add calcium and vitamins to diet. • Weight bearing activities and exercise – walking, climbing, bike riding. • May need to replace bi-focal lenses with 2 pairs of glasses. • Evaluation of medications for impact on bone density – meds used for seizures/ mood stabilization/ SSRI's can lower • Evaluation of medications – impact on balance – diuretics, BP, urinary frequency 	<p>An endocrinologist is typically the medical “specialist who manages osteopenia or osteoporosis.</p> <p>Keep person with PWS mobile. Once becomes wheelchair dependent –increases many more health risks – blood clots, pulmonary emboli.</p> <p><u>Resource:</u> Osteoporosis Evaluation & Therapy in PWS – Consensus Statement of PWSA (SA) Clinical Advisory Board</p>

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Low Bone Density, Degenerative Changes and Mobility Issues cont.			<ul style="list-style-type: none"> Stabilize balance: proper fitting shoes, guardrails, walkers/canes, one-story homes. 	
Circulation / Vascular Problems	<ul style="list-style-type: none"> Diabetes Open sores and/or cuts Cardiac/heart problems High blood pressure Sedentary life style 	<ul style="list-style-type: none"> Hemoglobin A1C, blood sugar monitoring BP monitoring Blood lipid testing 	<ul style="list-style-type: none"> Early diagnosis and management of diabetes Avoid prolonged periods of sitting Proper support of feet when sitting Prompt attention to cuts or sores – especially in lower extremities Proper fitting shoes – avoid thong type shoes Circulation stockings (make sure do not impair circulation) Proper hydration Walking 	<p>If person with PWS has diabetes and/or heart disease, additional, more extensive testing may be indicated.</p>
Diabetes	<ul style="list-style-type: none"> Obesity Family history Age Fat distribution Inactivity Race – African American, Hispanic, American Indian and Asian-Americans at greater risk 	<ul style="list-style-type: none"> Hemoglobin A1C, blood sugar monitoring Kidney blood testing – creatinine, BUN Blood lipids – cholesterol, triglycerides, HDL, LDL Annual eye exams 	<ul style="list-style-type: none"> Early diagnosis of diabetes and ongoing monitoring of blood sugars Adherence to diet and medication treatment Close monitoring of cuts and open sores – at high risk of developing cellulitis. Exercise – keep active 	<p>*Diabetes impacts almost every body system – vision, heart, blood vessels, kidney, . The earlier the onset – the greater the chances of complications. Management very important in preventing and/or minimizing complications.</p>
Change in Bowel Habits	<ul style="list-style-type: none"> Chronic issues with constipation Inadequate intake of water/fluids Inadequate fiber Low muscle tone Low activity level Medications Other health problems – low thyroid 	<ul style="list-style-type: none"> Rule out other causes of intestinal slowing – thyroid, colon cancer 	<ul style="list-style-type: none"> Monitor frequency & consistency of stool Keep moving and active Make the time – develop schedule for having a BM Adequate fluid intake Diet – use of pro-biotic foods, fresh fruits & vegetables, increase fiber Consult MD for use of laxatives Evaluate side effects of medications – mood stabilizers Medication Caution – anti-diarrheal and strong pain medications 	<p>*Reports of higher incidence of intestinal slowing and obstruction in aging adults with PWS.</p>

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Infections and Other Treatable Causes of Memory Problems	<ul style="list-style-type: none"> Infections – urinary tract infections, pneumonia Low thyroid Vit. B12 deficiency High/low blood sugar Low oxygen level Medications Depression Dehydration Heat stroke 	<ul style="list-style-type: none"> Urinalysis Chest x-ray Complete blood count – White blood count Thyroid Vit. B12 level Oxygen level Evaluate for depression MRI 	<ul style="list-style-type: none"> “Acute Confusion” – any sudden onset of memory problems should be evaluated by a health care professional Treat infections – antibiotics, fluids, Treat thyroid and/or Vit. B12 deficiency Blood sugar management Supplemental oxygen therapy Evaluate medications – Health care professional may make dosage adjustment and/or stop Treat depression Rehydrate Remove from heat; Call 911 – MEDICAL EMERGENCY; start cooling measures; 	<p>Each situation must be evaluated and treated individually.</p>
Dental Problems <ul style="list-style-type: none"> Tooth sensitivity Enamel loss 	<ul style="list-style-type: none"> Lifelong problems with cavities and abnormal production of saliva Poor oral/dental practices Excessive intake of carbonated beverages and/or juices high in acid Undiagnosed gastric-esophageal reflux (GERD) 	<ul style="list-style-type: none"> Dental exams at least every 6 months. GI workup to determine cause of enamel loss – Upper GI x-ray, Endoscopy 	<ul style="list-style-type: none"> Use toothpaste for “tooth sensitivity” Brush teeth at least 2 times daily Use incentive programs for good oral/dental care Limit intake of carbonated beverages and/or juices high in acid <ul style="list-style-type: none"> Dilute juices with water Investigate cause of enamel loss Once determined – treat cause. If GERD – medications, elevate head of bed while sleeping, sit upright 1 hour after eating May require softer foods – cooked not raw vegetables, ground meats. 	<p>*It is extremely challenging securing dental services for persons on Medical Assistance– nationwide. Most states have dentists that are willing to take on some patients in a “donated services” capacity. In many cases – there are waiting lists. Check website below for further information and other programs to assist with dental care for the disabled. http://www.nfdh.org/donated-dental-services-dds/state-dds-programs</p>
Urinary Incontinence <ul style="list-style-type: none"> Stress – caused by pressure – coughing, sneezing, weight, stool in colon Urge – may be caused by infection or nerve problem “Overflow” – caused by an obstruction (enlarged prostate), tumor 	<ul style="list-style-type: none"> Poor muscle tone Age Chronic problems with bedwetting Obesity Constipation Low hormone levels Medications Too much caffeine 	<ul style="list-style-type: none"> Urinalysis Other testing for related health problems Evaluate hormone levels – natural decrease as we age See urologist to rule out other urologic problems 	<ul style="list-style-type: none"> Kegel exercises – starting and stopping the flow of urine (Make it a game!) Bladder training – urinating at set intervals of time. Address obesity and constipation Review medications – side effects and time of administration. Limit amount of caffeine Avoid fluids in the evening. Medications may help with some cases Pads / diapers (may only need at certain times). 	<p>Other health problems – infections, diabetes, enlarged prostate, seizures, multiple sclerosis, kidney problems – can contribute to urinary incontinence. Age can reduce the amount of urine your bladder can hold. Many people with urinary incontinence limit fluids and increase risk of a urinary tract infection.</p>