

MANAGEMENT GUIDELINES FOR ADULTS WITH NEUROFIBROMATOSIS TYPE 1 (NF1)



EMPOWERING INDIVIDUALS WITH NF

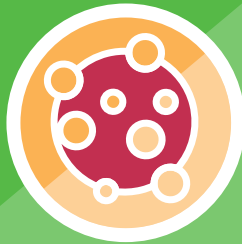
OVERALL RECOMMENDATION

All adults with NF1 should be assessed by a physician at least once a year with particular attention paid to blood pressure and age-related complications. While all symptoms should be investigated promptly, additional routine screening of asymptomatic patients is not recommended. The disease mainly affects the skin and nervous system. However, there are many potential complications that must be assessed.

TUMOURS

Ask your doctor to examine lumps and bumps — anywhere on your body, whether painful or not — that are growing or changing. Progressive/persistent pain and rapid growth relating to plexiform tumours can be a warning sign of a possible MPNST (malignant peripheral nerve sheath tumour). Early detection and surgical removal are recommended.

Dermal (relating to the skin) neurofibromas can be removed by surgery, laser removal or electrodesiccation. No one method has been shown to be superior to the others.



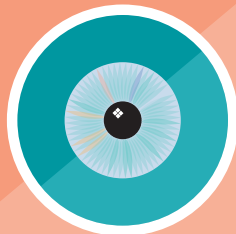
NEUROLOGICAL ISSUES

If you experience unusual headaches, seizures, visual disturbances, nerve pain, or gait disturbances, be sure to request an immediate referral to a neurologist.



VISION ISSUES

Some people with NF1 may have experienced eye problems as children (especially optic nerve tumours, which occur in roughly 5% of children.) Whatever your vision issues as a child, seek assessment from your physician if you experience any visual symptoms.



CARDIO- VASCULAR ISSUES

People with NF1 often have high blood pressure. Symptoms include episodes of headache, sweating, or a racing heartbeat. Be sure your doctor checks your blood pressure *on every visit* or at least once a year. Other cardiovascular issues may arise and should be monitored by a specialist.

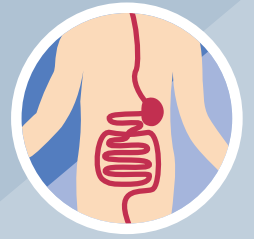


BONE HEALTH



Men and women with NF1 have an increased risk of osteoporosis. Ask your doctor to examine your risk factors and to suggest diet and exercise options, particularly if you are female and close to menopause.

GASTRO- INTESTINAL ISSUES



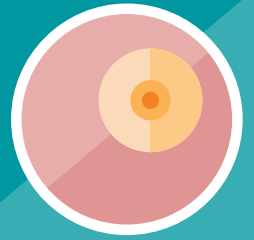
If you have bloating, pain, constipation or bleeding, seek immediate medical attention.

PREGNANCY



Genetic testing prior to pregnancy will reveal the risk you have of passing NF on to your children. There is currently a 1-2 year wait for such results, so seek genetic testing well before you wish to consider pregnancy. Women with NF1 need additional monitoring during pregnancy.

BREAST CANCER RISK IN WOMEN



Women with NF1 have an increased breast cancer risk between ages of 30 and 50 years. During this time, annual screening is recommended. This can include a mammogram and breast MRI. Patients can be referred to the BC Cancer Hereditary Cancer Program's High Risk Clinic for discussion of the breast cancer risk and for coordination of screening.

PSYCHOLOGICAL ISSUES



The pressure and stress of carrying a genetic disorder is considerable for both men and women, no matter how severely you are affected. If you need counselling, be sure to seek it out. Look for someone experienced in dealing with medical challenges. Contact the Tumour Foundation of BC for one-on-one support and patient/parent support groups.

FOR FURTHER INFORMATION:

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