



NAVIGATING HEALTH TRANSITIONS

A GUIDE FOR YOUNG ADULTS WITH NF

CONTENTS

INTRODUCTION	1	INSURANCE AND FINANCIAL CONSIDERATIONS	6
Understanding Neurofibromatosis	1	Medical Services Plan (MSP)	6
Neurofibromatosis Type 1 (NF1)	1	BC Services Card	6
Neurofibromatosis Type 2 Related Schwannomatosis (NF2-SWN)	1	Financial Assistance	6
Schwannomatosis.	1	I am living with a disability related to my NF, where can I get help?	7
HOW TO TRANSITION INTO ADULT HEALTH CARE	2	What about Food Banks?	7
Where Do I Go From Here?	2	EDUCATIONAL AND EMPLOYMENT TRANSITION	7
ADULT CARE PROVIDERS AND SPECIALISTS	3	How Do I Access Financial Educational Support?	7
Who Will Manage My Medical Care and NF Once I Leave My Pediatric Team?	3	What Can I Do If I Require Some Educational Assistance or Learning Support?	8
Adult Care Specialists:	3	Learning Resources:	8
Specialists:	3	How Do I Get Help With Employment?	8
SCREENING AND DIAGNOSTIC TESTS FOR NF	4	SOME TIPS FOR GETTING A JOB:	8
Persistent or night time pain	4	PSYCHOSOCIAL AND EMOTIONAL SUPPORT.. 9	
What Should I Do If I Have a Medical Emergency?.	4	Support and Resources	9
Who Can I Talk to About a Non-Urgent Medical Concern If I Cannot Reach My Doctor?	5	POSITIVE BODY IMAGE	9
HEALTHCARE SUPPORT SERVICES	5	What Can I Do To Develop a Positive Body Image?	10
Who Else Can Help Me on My Healthcare Journey With NF?	5	FAMILY PLANNING	10

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

SELF ADVOCACY AND EMPOWERMENT.....11	REFERENCES AND RESOURCES 16
How Do I Talk To My Doctor	<i>StudentAidBC</i>16
So That I Am Heard?11	<i>BC Children’s Hospital (BCCH)</i>16
What Are Clinical Trials?11	<i>British Columbia Income Assistance</i>16
How Do I Find What Clinical Trials	<i>WorkBC</i>16
Are Available Right Now?12	<i>HealthLinkBC</i>16
NF RESEARCH AND CLINICAL TRIALS..... 12	<i>Tumour Foundation of BC.</i>16
Advancements in the Diagnosis of	<i>National Organization for Rare Diseases.</i>16
Neurofibromatosis Type 2 -related	<i>Mental Health and Substance Use Information</i>
schwannomatosis (NF2-SWN) and	<i>you can trust</i>16
Schwannomatosis.12	<i>The NF2 Crew</i>16
NFlection Therapeutics Clinical Trial Reveals	<i>Government of British Columbia</i>16
Positive Results12	<i>Disability Alliance BC</i>16
Koselugo Offering Hope for NF1 Patients	<i>Wellness Together Canada</i>17
With Inoperable Symptomatic Plexiform	<i>Immediate Virtual Mental Health Support</i> . . .17
Neurofibromas.12	<i>Foundry Virtual BC</i>17
CONCLUSION..... 13	<i>YMCA Mental Wellness Programs</i>17
GLOSSARY OF TERMS..... 14	<i>Body Image, Self-Esteem and Mental Health</i> .17
CONTACT INFORMATION..... 15	<i>Changing Faces: Positive-thinking techniques</i>
<i>Anxiety Canada</i>15	<i>for people with a visible difference.</i>17
<i>BC Housing</i>15	<i>BC Women’s Hospital and Health Centre</i>
<i>Disability Alliance BC</i>15	<i>Medical Genetics Clinic.</i>17
<i>HealthLinkBC</i>15	<i>CISION PR Newswire</i>17
<i>Pain BC</i>15	<i>NIH National Library of Medicine:</i>
<i>Tumour Foundation of BC.</i>15	<i>ClinicalTrials</i>17
<i>Self-Management British Columbia</i>16	



INTRODUCTION

Neurofibromatosis or NF, is a genetic disorder that affects more than 4 million people worldwide. NF can be inherited from a parent or NF or just show up by itself because of changes in genes. Anyone can be affected. People living with NF have tumours that grow on nerves throughout the body.

Although there is no cure for NF, promising research is underway and advancements in treatments are becoming a reality.

Children with NF normally receive health care from a pediatric team until they reach 18 years of age. Around this time, the young adult will need to transition into the adult health care system, and will no longer have access to the pediatrician. During this phase, the young person will need to become increasingly independent in managing his or her own medical care. This handbook provides helpful information to make this experience of entering into adult health care less challenging.

UNDERSTANDING NEUROFIBROMATOSIS

Neurofibromatosis is a genetic disorder with three distinct types- NF1, NF2- related schwannomatosis (NF2-SWN) and Schwannomatosis.

People affected by NF can have tumours that may affect the brain, spinal cord, and the nerves that send signals between the brain and spinal cord affecting other parts of the body. These tumours are usually noncancerous, but sometimes can progress to cancer (malignant). Some people living with NF have mild symptoms, while others have learning disabilities, heart problems, vision problems, significant pain, and hearing loss. These NF disorders affects individuals from different ethnic groups around the world, and they occur in both men and women.

NEUROFIBROMATOSIS TYPE 1 (NF1)

This is the most common type of NF, and it affects 1 in 2500 people worldwide. Common symptoms for people with NF1 are café au lait (pale brown) skin spots and small benign growths on or under the skin known as cutaneous neurofibromas. Freckling in the underarms and in the groin are also common. Approximately half of the people living with NF1 have learning disabilities. Some people may have curving and softening of the bones and spine. Occasionally, tumours can grow in the brain, on cranial nerves, or along the spinal cord. Typically NF tumours are benign (not cancerous), however, in a small percentage of patients, a benign tumour may become cancerous. Some tumours cause pressure on different body tissues, and this can lead to health problems that need to be monitored and managed.

NEUROFIBROMATOSIS TYPE 2 RELATED SCHWANNOMATOSIS (NF2-SWN)

NF2-related schwannomatosis is a rare type of NF, affecting 1 in 20,000 worldwide. People living with this disorder have benign tumours called vestibular schwannomas on the nerve that carries sound and balance information from the ear to the brain. Both ears may be affected by these tumours leading to partial or complete hearing impairment or hearing loss. The eyes may be affected by cataracts or other visual challenges. Other tumours may grow along the spine or in the brain, however, these are usually non cancerous growths.

SCHWANNOMATOSIS

Schwannomatosis is a rare form of NF, affecting fewer than 1 in 70,000 people worldwide. It results from a genetic mutation affecting nerve cell growth regulation, leading to the formation of tumours known as schwannomas. These tumours arise from Schwann cells, which typically protect nerve fibers but grow abnormally in this disorder, mainly on spinal and peripheral nerves. As a result, communication between the brain and

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

the body becomes challenging, causing pain, numbness, weakness, and complications in bowel, urinary, vision, and headache-related functions for those affected.

HOW TO TRANSITION INTO ADULT HEALTH CARE

Most youth transition out of pediatric care between 18 and 21 years of age, into the adult health care system. If you have been receiving care in a pediatric clinic or hospital setting your pediatric team will let you know when it is time for you to start this process. Don't be afraid to ask questions and to seek recommendations and referrals from the pediatric professionals that know you best. The goal is for you to gain confidence, skills, and have the information you need to become more independent in managing your health

WHERE DO I GO FROM HERE?

- Ask your pediatric team to point you in the right direction as you move into adult health care.
- BC Children's Hospital has a special resource called ON TRAC to help youth, families, and care providers prepare for adulthood and for adult health care. This resource provides a Youth Toolkit and Family Toolkit with information and resources to help you. You do not need a referral to use this service.
- *Visit the [BCCH website for more information and help using ON TRAC:](#)*
- Keep track of your health care appointments, new doctor referrals, tests, medications and any changes in your treatment plan in a folder or in a secure file on your electronic device. Keep a list of contacts of your health care providers, use your calendar to record appointments, and keep

notes about your NF symptoms, medications, or questions for your doctor.

- Request for your health records to be transferred from your pediatric team to the new health care professional in adult care. You may be directed to contact the Health Records Department of the hospital, to sign a Release of Health Records Form, before your medical files can be sent off to your new doctor. It is extremely important for your new adult health care team to have your previous test reports, specialists reports, and all of your pediatric health care records to ensure a smooth transition and accurate medical care moving forward.
- Find and establish a good working relationship with a family doctor (GP) or nurse practitioner. In adult health care, the family doctor helps to direct your medical care, orders most screening tests, and makes referrals to specialists you may need in your NF care. Have an honest and open conversation with your doctor about your NF, your symptoms, and any worries you have about your health. Don't be afraid to educate your doctor about your NF and to request a referral to a specialist, such as a Neurologist that has more experience in this area.
- *If you don't already have a family doctor, register with [Health Connect Registry](#) [HealthLinkBC](#) to receive help in finding a doctor or nurse practitioner:*



ADULT CARE PROVIDERS AND SPECIALISTS

WHO WILL MANAGE MY MEDICAL CARE AND NF ONCE I LEAVE MY PEDIATRIC TEAM?

This is a common question for young people and their families living with NF. Your medical care including your NF will be managed by your family doctor or nurse practitioner. Your family doctor will oversee your health care and refer you to any specialists needed. Make sure that you have a conversation with your practitioner about your NF and your current concerns. Some family physicians have limited experience taking care of NF patients, and are interested in gaining more knowledge about the disorder. Please share the following Tumour Foundation of BC “Management Guidelines for Adults with Neurofibromatosis” resource with your new health care provider:

This pamphlet will provide valuable information to your doctor about signs and symptoms to monitor with your NF1, screening tests to order, and possible needed referrals to specialists.

ADULT CARE SPECIALISTS:

People living with NF will often require a medical referral to a specialist to manage their NF. These referrals are usually initiated by your family doctor or nurse practitioner. You will only need a referral to one or some of these specialists if you have specific health problems or symptoms that need more specialized care, more than what your family doctor can manage.

SPECIALISTS:

Neurologist: a doctor who diagnosis, treats and manages disorders of the brain and nervous system.

Endocrinologist: a doctor who treats conditions related to hormones and who specializes in conditions such as diabetes, menopause, and thyroid problems.

Dermatologist: a doctor who specializes in conditions that affect the skin, hair and nails.

Surgeons: Plastic Surgeons, ENT (Ear, Nose and Throat) Surgeon, Orthopedic Surgeons, Neurosurgeons or General Surgeons: these doctors perform various types of surgeries and different surgeons work on different areas of the body using a variety of techniques.

Psychiatrist: a doctor who specializes in mental health, including substance use disorders. They treat mental, emotional, and behavioural disorders. A psychiatrist is a medical doctor who can prescribe medications.

Psychologist: specializes in the study of human thought and behaviour and offers practical and behavioural techniques and advice to patients. A psychologist does not prescribe medication.

Ophthalmologist: a doctor who treats eye diseases, performs eye surgery and prescribes medications.

Geneticist: a doctor who studies genetics and family traits and how they affect individuals and families.

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



Tumour
Foundation
of BC

SCREENING AND DIAGNOSTIC TESTS FOR NF

Remember that although malignant (cancerous) peripheral nerve sheath tumours are rare, early detection is extremely important! Please refer to the Tumour Foundation of BC Educational Info Sheet: *Self-Monitoring Malignancies in NF*:

- **Follow up with your primary care doctor** at least once a year, and more frequently if needed. Your doctor should **inspect the skin, monitor your blood pressure and assess you for any neurological problems**. Communicate any worrisome symptoms to your doctor including any overwhelming sadness, anxiety, and symptoms in your body that are new to you.
- **Annual breast cancer screening** is recommended for NF female patients ages 30-50, and earlier if there is a family history or you have noticed any lumps or other concerning symptoms in your chest area. Ask your doctor if you can be referred to the Hereditary Breast Cancer program if available in your area.
- **MRI of the brain and spine** is recommended for NF patients to check for any possible tumours along the spine and in the brain. This MRI is to be repeated yearly if lesions or tumours are found and a referral to a Neurologist is recommended.
- **Genetic testing/counselling** is recommended if you desire to start a family and prior to getting pregnant.
- Eye exams to screen for Lisch nodules, cataracts and vision problems.
- **Hearing exams** for people with NF2-related schwannomas

You know your body best, trust your instincts and don't be afraid to speak up when something in your body doesn't feel right, look right, or worries you.

REMEMBER TO GET **HELP** FROM YOUR DOCTOR IF YOU HAVE THE FOLLOWING SYMPTOMS:

- H**ard texture of the tumour
- E**nlarging rapidly
- L**imb weakness, numbness, clumsiness
- P**ersistent or night time pain

PERSISTENT OR NIGHT TIME PAIN

Additional signs and symptoms to self-monitor for: breathing issues, new symptoms coming from any affected organ, swallowing difficulty, weight loss or night sweats, bowel or bladder problems, new neurological symptoms such as weakness, numbness or tingling:

WHAT SHOULD I DO IF I HAVE A MEDICAL EMERGENCY?

A Medical Emergency can happen when you least expect it and you need to know just what to do.

Call 911 if you need immediate medical assistance!

REMEMBER THE **ABC**S

- A-AIRWAY**
- B-BREATHING**
- C-CIRCULATION**

If you are having any symptoms that prevent you from breathing properly or your lungs and throat feel too tight, *call 911!*

If you are bleeding uncontrollably or are experiencing heart problems such as chest pain or an abnormally fast heart rate, *call 911!*

If you feel dizzy or feel like you may faint, *call 911!*

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

Be prepared ahead of time by learning how to contact 911 quickly from your cell phone or your landline. During a stressful event, you may forget the number, therefore post it nearby close to your phone to help you remember.

If you are concerned about a possible poisoning or exposure to a toxic substance, call the Poison Control immediately at **1 800 567-8911**

WHO CAN I TALK TO ABOUT A NON-URGENT MEDICAL CONCERN IF I CANNOT REACH MY DOCTOR?

If you have a medical question or concern and you cannot speak with your doctor,

Call 8-1-1 HealthLinkBC: This is a free service for BC residents, it is open 24 hours a day and you will be able to speak with a Registered Nurse.

You can also search for medical services, guides and fact sheets, illnesses and conditions, immunization information and to email your questions to a registered dietitian or exercise professional:

When speaking to emergency services or to any other health care professional that doesn't know you, it is important to let them know that you have Neurofibromatosis and let them know if you need any special accommodations such as assistive technologies or translators.

HEALTHCARE SUPPORT SERVICES

WHO ELSE CAN HELP ME ON MY HEALTHCARE JOURNEY WITH NF?

You are not alone! Allow trusted family, friends, organizations, and community supports to come along side you on your journey to optimal health.

The Tumour Foundation of BC: We have supported individuals and families living with NF since 1984. Check our website for details of support services we offer. These services include: One-on-one support, NF support line and support group, annual conference, educational resources, educational scholarships, the INSPIRE magazine, community awareness and fundraising efforts, patient advocacy, supporting research, and so much more.

HealthLinkBC: This BC service provides free urgent Telehealth 811 services, provides information regarding urgent primary care centers, community public health announcements, and online health related information at your fingertips.

British Columbia Mental Health Support Line

Here to Help: Mental Health and Substance Use Information you can trust

CrisisCentreChat.ca: online chat with a crisis responder

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

Anxiety Canada: is devoted to providing accessible, science-based anxiety relief to help you live the life you want. They provide free and affordable resources for those struggling with anxiety and anxiety disorders. Visit their website to learn more about their programs, tools, and resources

Canadian Health Advocates Inc. (CHAI): has a growing network of health advocates across Canada.

Canadian Organization for Rare Diseases (CORD):

The NF2 Crew: is one of the largest NF2 support groups in existence, they connect through various internet-based communication options, mainly Facebook.

tests such as X-rays and various blood tests. Please refer to the Ministry of Health website for information about enrollment, and the services covered:

BC SERVICES CARD

Each B.C. resident enrolled with the Medical Services Plan (MSP) is eligible for a BC Services Card.

The BC Services Card has a unique lifetime identification number called the Personal Health Number (PHN). Please keep this card and your PHN safe and with you at all times, you will need this to fill prescription medications, to access health care services such as doctor visits, going to the hospital, and even for getting tests such as blood work. You may be asked to show your BC Services Card as a form of Identification to confirm who you are.

You can find more information about your PHN and the BC Services Card on the Government of BC website:

INSURANCE AND FINANCIAL CONSIDERATIONS

MEDICAL SERVICES PLAN (MSP)

All residents of British Columbia must enrol with the Medical Services Plan (MSP). This is the provincial health insurance program that covers health care benefits for BC residents. This plan covers medically necessary services provided by physicians and midwives, dental and oral surgery performed in a hospital, eye examinations if medically required and some orthodontic services. In addition, MSP pays for many required diagnostic

FINANCIAL ASSISTANCE

If you find yourself in need of financial assistance because your income is insufficient to cover your basic needs, or you can't work at all, there is help available.

You may be eligible for income assistance through the Province of British Columbia. You can check online to see if you qualify for this financial help and you can submit your application online:

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

I AM LIVING WITH A DISABILITY RELATED TO MY NF, WHERE CAN I GET HELP?

Some people living with NF have a disability that prevents them from being able to work, for example, a significant vision, hearing, or chronic pain challenge.

There are many programs and services available to you if you have been designated as a Person With Disabilities (PWD). Your doctor or nurse practitioner will complete some forms to outline the details of your disability to help you access these valuable resource.

If you would like to find out more about disability assistance and access application forms, visit:

The Disability Alliance BC is a non-profit organization that offers help and guidance to people living with disabilities:

WHAT ABOUT FOOD BANKS?

If you cannot afford to buy enough food, you may be able to receive free food from a food bank near you. Some food banks can even help you find other services in the community. To receive food, you may have to prove that you have a low income.

To find a Food Bank in British Columbia, visit:

EDUCATIONAL AND EMPLOYMENT TRANSITION

Graduating from high school is an exciting time. You can feel a sense of pride and accomplishment at reaching this milestone. You may be wondering where to go from here, should you get a job right away or do you want to pursue a college or career training course? When deciding about courses to study or what type of job you want, think about what you enjoy doing and what you are good at. Do you feel your best when you are around other people, are you hands on and crafty, do you love technology, what are your passions? Only you can answer this question, you know yourself best, however, you may want to ask the trusted people in your life for their input.

HOW DO I ACCESS FINANCIAL EDUCATIONAL SUPPORT?

If you would like to go to college or take a trades or career course, you may be eligible for financial assistance from StudentAidBC. This BC government service helps young adults pursue and education while providing various grants, scholarships, and other financial supports.

Learn more about the help available and access application forms:

Did you know that the Tumour Foundation of BC offers educational scholarships for students in British Columbia impacted by NF? If you're pursuing higher education at a university, college, trade school, or post-secondary learning center, you can apply for this special scholarship conveniently through our website.

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

WHAT CAN I DO IF I REQUIRE SOME EDUCATIONAL ASSISTANCE OR LEARNING SUPPORT?

If you have a learning disability and you require some learning or educational assistance, there are services available to you.

LEARNING RESOURCES:

Colleges offer learning support to students who need it and ask for it. This assistance is most often included in the program tuition cost, therefore, you will not pay any additional fees.

Don't be afraid to talk to or email the college student advisor to request the help you need. You may need to register through Student or Disability Services. Make sure that you are clear about what you are asking for. You may need a longer time limit to write an exam, or need an extended due date for an assignment, these are common requests that are fulfilled. If you need a staff member to read out the exam questions to you, or you find it easier to use an adaptive electronic device in the classroom, the college should be able to accommodate your request. **When making your request, make sure to provide a reason, for example the learning disability that you have, your medical diagnosis, or any other details to ensure that you will receive help.**

Any personal information you provide school officials will be kept private, you choose who you want to share your NF story with and when.

It is up to you if you want to talk about your NF with classmates and new friends. College is an exciting new adventure, allow yourself to have fun and to make new friends!

HOW DO I GET HELP WITH EMPLOYMENT?

Some individuals living with NF do not desire to attend college or to continue their education after high school, they choose to seek employment

instead. If you decide to enter the workforce, you may wonder how to go about it.

SOME TIPS FOR GETTING A JOB:

Have your personal documents ready, such as S.I.N (Social Insurance Number), birth certificate, you reference person's name and contact information, or a reference letter from a trusted adult such as a teacher, previous boss, or anyone who can vouch for you.

- **Spread the word to family and friends that you are looking for a job!**
- **Check online job boards and websites such as INDEED CANADA to find and apply for jobs.**
- **Don't get discouraged, people often apply for several jobs before they are offered one.**

If you find yourself in need of income assistance, there is help for eligible BC residents. To find out if you qualify and to apply for assistance:

WorkBC is another free resource for BC residents. You may want to visit a WorkBC Centre near you for employment help, information about disability assistance, access to computers, resume and cover letter tools, and many additional services.

Visit the website to learn about current job postings, training opportunities, and employment services:

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

PSYCHOSOCIAL AND EMOTIONAL SUPPORT

Living with a rare chronic disorder like NF can affect your physical, mental, emotional, and spiritual health. The transition from pediatric health to the adult health care system can be stressful. It is important to open up to the people in your life that you trust the most, those are the people that care about you and want the very best for you. Having someone to walk along side you on this health journey will help you feel supported during this transition.

If you find yourself overwhelmed with negative thoughts, fears, and emotions that make it hard to enjoy life or perform your regular activities of daily living, talk to your doctor and your trusted support person. You don't have to do this alone! Your doctor or nurse practitioner can make a referral for you to a specialist such as a psychologist or psychiatrist to treat any underlying mental health issues.

SUPPORT AND RESOURCES

The Tumour Foundation of BC is a safe community for people living with NF and for their families. Visit our website to access free educational resources, join the online NF support group, keep up to date with NF research and fundraising events, learn about grants, and much more.

Wellness Together Canada can provide much needed counselling services to support you. This organization provides free resources for mental health and substance use support. You can visit the website to discover more information and the resources available:

310 Mental Health Support is a free virtual telephone help line for any British Columbia resident who needs immediate emotional support and who needs information about resources specific to mental health. Call 310-6789 to speak to a trained Mental Health Support representative. For more information, visit:

Foundry Virtual BC provides access to virtual services through the Foundry BC app-co-created with and for youth and caregivers in British Columbia. You can access this service if you are between the ages of 12-24. Visit the Foundry website for more information:

Y Mind: YMCA Mental Wellness Programs: Free online programs for young people aged 13-30. This program helps young people cope with stress, worry and anxiety. Y Mind Adult supports adults ages 31+ and led by mental health professionals, it helps participants learn strategies to increase coping skills:

POSITIVE BODY IMAGE

Body image is the mental picture that you have of your body and the way you feel about your reflection when you look in the mirror. Having a positive or healthy body image means that you accept and like the way you look and are not trying to change your body to please anyone else.

This healthy outlook will help you feel and look your best. Remember that having NF and outward signs such as cutaneous fibromas does not take away from the unique qualities and traits that make up who you are. You have special talents, insights, and

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

attributes that no one else has, notice all the good things that make up YOU.

WHAT CAN I DO TO DEVELOP A POSITIVE BODY IMAGE?

- Treat your body with kindness.
 - Eat healthy and exercise to help you feel and look your best.
 - Dress and present yourself to the world in a way that makes you feel good.
 - Spend time around people that love and care about you and accept you the way you are.
 - Remember that most people have a hard time maintaining a positive body image at times.
 - Become aware of media stereotypes that show unrealistic images, and focus on trying to reach impossible perfection.
 - Make a list of all of the positive qualities and achievements you have and look at it often to help you feel more confident. For example, “I am caring”, you can think of an example when your actions made someone else feel better, the time you walked the dog for your sick neighbour, or when you listened to a friend who was going through a difficult situation. Your kindness made a huge positive difference! What about other positive qualities that you have? Are you a good singer, can you draw, are you a talented dancer or cook?
 - The **Changing Faces** website offers helpful tips about positive-thinking techniques for people living with a visible difference, visit the website for more information:
-
- If you would like to explore your options for removal of cutaneous fibromas, talk to your doctor and ask for a referral to a specialist such as a dermatologist, or plastic surgeon who has experience with caring for people living

with NF. Some fibromas can be removed by surgery or laser. **Remember to have realistic expectations, you may not be able to have all of your fibromas removed.**

- Here to Help is a virtual resource that has tools and information about body image and self-esteem:

FAMILY PLANNING

If you are thinking about starting a family and having children of your own, genetic testing is recommended to assess the risk of passing NF to your children. Asking your health care provider for a referral to a geneticist is best done early, currently in BC, there is a 1-2 year wait list for this genetic testing.

If you have NF1 or NF2-SWN, there is a 50% chance of passing it to any future children. It is often difficult to predict how mild or severe your child’s symptoms of NF will be. Speaking to a genetic specialist or counselor will give you a better idea of the risks, options, or any alternative ways of starting a family. You will be able to make the best-informed decision once you have met with a geneticist and had testing.

BC Women’s Hospital and Health Centre has medical genetics clinic offering genetic testing, counselling, and education. Appointments are in person, or by telehealth via phone or video conference. Visit the website to learn more:

You do need a referral from a health care professional such as your family doctor, to be seen in the Medical Genetics Program.



SELF ADVOCACY AND EMPOWERMENT

Now that you are transitioning from pediatric to adult health care, you will be in charge of managing your health care, scheduling your own appointments, and attending visits with your doctors and specialists. Being empowered, means having power and control over your life, you are respected, confident and have equal rights in society.

Being your own **self advocate** means that you are able to speak up for yourself and the things that are important to you, you can ask for help, and you can express how you feel. You know your rights and you are able to make decisions that affect your life and accept the consequences for the choices you made.

You have the right to speak up, be heard, and be taken seriously!

HOW DO I TALK TO MY DOCTOR SO THAT I AM HEARD?

- **BE PREPARED!** You will have only a few minutes to talk to your doctor during the appointment, so get the most out of your visit by preparing ahead of time. Write down your concerns and questions ahead of time and bring these notes with you to your appointment.
- **Bring your health information with you to your appointment**, this will assist the doctor to get to know you if you're a new patient. You know your health best, you know if your medications have changed, if you have new symptoms, or if you recently saw a new specialist. If you monitor your blood pressure, bring the print out of the readings or a notebook with the measurements, if you have new symptoms that worry you, bring your journal to refer to dates, times, and general symptom diary notes.
- **Bring a list of your current medications** to your doctor appointment.

- **Ask a trusted family member or friend to accompany you** to the appointment.
- **Make eye contact and speak up.**
- **Ask for what you need respectfully.** For example, if you need a test that you know is recommended for patients living with NF, explain calmly that due to your NF you need the test in question, it will help to screen for malignant tumours, or breast cancer, or any other possible complications that the test may screen for. Offer your doctor the pamphlet resource created by the Tumour Foundation of BC: [*Management Guidelines for Adults With Neurofibromatosis Type 1*](#). You will find this free resource on our website, you may download it or print a copy to take to your physician:
- **Ask questions** if you don't understand what the doctor is telling you, ask if he or she can explain it again, draw a picture, or provide you with a pamphlet to review at home.
- **Take notes** during the appointment including any instructions that your doctor gives you.
- **Ask your doctor for permission to record the appointment** to help you correctly remember everything.
- **Be respectful** even when you are frustrated or you disagree, and don't give up.
- **Ask for what you need or express your concerns again** if the first time you felt ignored.
- Don't accept a treatment or give consent until you are well informed of all the options, potential risks and potential benefits.

WHAT ARE CLINICAL TRIALS?

Clinical trials are research studies that test a new medical, surgical, or specific treatment in volunteers. These trials help scientists and researchers figure out if a new treatment such as

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

a new medication, is safe and effective in people. Many of the effective medical treatments that we use today were made possible by clinical trials.

HOW DO I FIND WHAT CLINICAL TRIALS ARE AVAILABLE RIGHT NOW?

- For a full list of clinical trials, and whether or not they are recruiting volunteers visit:
- To view a list of NF related clinical trials in British Columbia visit:

NF RESEARCH AND CLINICAL TRIALS

Great strides in neurofibromatosis research are underway, leading to a better understanding of the disorders, and to promising advancements in treatment options. This is exciting news for the NF community, we have more reason to hope than ever before!

ADVANCEMENTS IN THE DIAGNOSIS OF NEUROFIBROMATOSIS TYPE 2 -RELATED SCHWANNOMATOSIS (NF2-SWN) AND SCHWANNOMATOSIS

- Did you know that we now have updated criteria for NF2-SWN and Schwannomatosis that combines both the clinical symptoms and uses genetic testing to differentiate the two unique conditions?
- The updated diagnostic criteria for schwannomatosis classify each disorder according to the specific gene carrying a pathogenic variant. Therefore, NF2 is now termed NF2-related schwannomatosis (NF2-SWN)

- The discovery of the specific genes that cause NF1, NF2, and schwannomatosis are paving the way to not only understanding the disorders better, but also to making progress in the development of treatments.

NFLECTION THERAPEUTICS CLINICAL TRIAL REVEALS POSITIVE RESULTS

- Exciting news for people living with NF1 who are interested in advancements in the treatment of cutaneous neurofibromas.
- In this Phase 2b study, The NFX-179 Gel, a topical medication, showed significant reduction in the size of CNFs and it was tolerated by most study participants. This drug is in clinical trial in the US.

KOSELUGO OFFERING HOPE FOR NF1 PATIENTS WITH INOPERABLE SYMPTOMATIC PLEXIFORM NEUROFIBROMAS

- Koselugo (selumetinib) is the first and only Health Canada approved medicine for the treatment of pediatric patients aged 2 years and above for symptomatic, inoperable plexiform neurofibromas (PN). Clinical trials are underway to test the medication in adults.
- Koselugo has also been recommended for funding by the Canadian Agency for Drug Technologies in Health (CADTH) for the pediatric population 2-18 years of age.
- This critical medication's efficacy reveals that effective treatments for NF1 are possible, and it opens the door to continued research and the development of even more treatments in the future.



CONCLUSION

Transitioning from pediatric to adult health care for young people living with NF is both an exciting and challenging time. This guide was created to support the NF community during this transition. Our deep hope is that you will feel empowered to embrace your independence, and to reach your full potential as you enter adulthood. The Tumour Foundation of BC is here to partner with you so that you don't have to walk this journey alone.



GLOSSARY OF TERMS

Acoustic Neuromas: tumours on the nerves that lead from the ears to the brain. These tumours can impair the ability to hear.

Bilateral vestibular schwannomas: Benign tumours on the eighth cranial nerve that cause hearing and balance disturbance in patients with NF2.

Biopsy: a tissue sample for testing purposes. This test is useful to determine if cells or tissue is cancerous or non cancerous.

Cafe au lait patches: birthmarks that are flat areas of darkened skin, anywhere from tan to dark brown. Six café au lait patches are a diagnostic of NF1, but occur in smaller numbers in NF2.

Cardiovascular disease: Includes congenital heart disease, especially pulmonary stenosis and hypertension associated with NF1.

Cutaneous neurofibroma: these tumours emerge along nerves, either on or beneath the skin, and are non-cancerous. They typically appear as small lumps, bumps, or nodules and might result in itching, stinging sensations, or aesthetic concerns. Depending on their placement, such as under a wristwatch strap or on the sole of the foot, they may also cause discomfort or pain.

Freckling: Benign skin pigmentation under the arms, around the neck, in the groins, diagnostic of NF1.

Heredity: the process of passing on characteristics or traits from a parent to a child.

Lisch Nodules: non-cancerous and asymptomatic raised pigmented lesions on the iris (coloured portion of the eye), seen in people with NF1.

Malignant: cancerous. A malignant tumour is a cancerous type of growth. These tumours can grow and spread to other areas of the body such as the lungs, liver, bones, or brain.

Malignant Peripheral Nerve Sheath Tumour (MPNST): is a cancer of the cells that form the

sheath that covers and protects the peripheral nerves. This can grow quickly and can spread to other parts of the body. Patients with NF1 have a 10% lifetime risk of developing a MPNST. Symptoms usually include continuous pain, alterations in texture, sudden and significant growth of a lump, or neurological issues.

Meningiomas: are tumours that arise from the meninges, the membranes that protect the brain and the spinal cord. Most of these tumours grow very slowly but sometimes they can cause serious disability as they compress nearby brain tissue, nerves or vessels. Meningiomas are the most common of the brain tumours.

MRI: Magnetic Resonance Imaging is a diagnostic test that creates detailed images of the body organs and structures using a large magnet and radio waves. This non invasive test can screen for tumours including areas such as the brain and spinal cord in NF patients.

Neruofibroma: Benign peripheral nerve sheath tumour that occurs on or under the skin or on the spinal nerve roots or nerve plexuses.

Neurofibromatosis type 1 (NF1): the most common type of NF, and is also one of the most common genetic neurological conditions. Symptoms can include multiple café au lait (light brown) skin spots, neurofibromas (small benign growths) on or under the skin, and/or freckling in the armpits or groin. Some people with NF1 also have learning challenges, scoliosis, and may develop tumours in the brain, and along the spine. Most tumours are non cancerous, although some may be malignant (cancerous).

NF2-related Schwannomatosis (NF2-SWN): formerly called NF2, and far less common than NF1. In this condition, benign tumours called vestibular schwannomas grow on the nerve that carries sound and balance information from the inner ear to the brain. These tumours affect both ears and

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

lead to partial or completed hearing impairment. The disorder can also cause cataracts leading to decreased vision.

Optic Glioma: a tumour that develops in the cells surrounding the optic nerve (controls vision). About 15% of children with NF1 will have an optic glioma and most of the time it will not cause symptoms or require treatment. Occasionally, an optic glioma can impair vision and may require treatment such as chemotherapy.

Pseudarthrosis: This condition related to NF1 leads to bending of long bones, often the shinbone (tibia). It happens when a bone breaks easily, even from small accidents during childhood, and then takes a long time to heal.

Plexiform Neurofibroma: a benign peripheral nerve sheath tumour that grows along the nerve, often involves multiple nerves frequently causing neurological deficit, and may undergo malignant

change in NF1. These can appear inside or outside the body. These often feel like cords or knots under the skin.

Renal artery stenosis: This is linked to high blood pressure in NF1 due to blood vessel abnormalities or aneurysms in the kidney.

Schwannomatosis: the least common form of NF. Benign tumours called schwannomas grow on nerves involving the spine and peripheral nerves. These tumours are caused by the abnormal growth of schwann cells (nerve covering). These tumours are non cancerous, however, they can lead to significant pain.

Scoliosis: a curvature of the spine. Scoliosis can occur in people with NF1.

Skin schwannomas: can appear as lumps under the skin, within the skin layers, or as patchy lesions on the skin in NF2- SWN.

CONTACT INFORMATION

ANXIETY CANADA

BC HOUSING

Applicant Services

Toll-free: 1-800-257-7756

DISABILITY ALLIANCE BC

Advocacy Access

Toll-free 1-800-663-1278

HEALTHLINKBC

Call: 8-1-1

Call to speak with a health services navigator or connect you directly to a registered nurse, dietitian, exercise professional, or a pharmacist.

PAIN BC

Toll-free: 1-844-430-0818

TUMOUR FOUNDATION OF BC

Toll-free: 1-800-385-2263

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

SELF-MANAGEMENT BRITISH COLUMBIA

Offers free programs for adults living with ongoing health conditions.

TOLL-FREE: 1-866-902-3767

REFERENCES AND RESOURCES

STUDENTAIDBC

BC CHILDREN'S HOSPITAL (BCCH)

BRITISH COLUMBIA INCOME ASSISTANCE

WORKBC

HEALTHLINKBC

TUMOUR FOUNDATION OF BC

**NATIONAL ORGANIZATION FOR
RARE DISEASES**

**MENTAL HEALTH AND SUBSTANCE USE
INFORMATION YOU CAN TRUST**

THE NF2 CREW

GOVERNMENT OF BRITISH COLUMBIA

DISABILITY ALLIANCE BC

NAVIGATING HEALTH TRANSITIONS: A GUIDE FOR YOUNG ADULTS WITH NF



**Tumour
Foundation
of BC**

WELLNESS TOGETHER CANADA

BC WOMEN'S HOSPITAL AND HEALTH
CENTRE MEDICAL GENETICS CLINIC

IMMEDIATE VIRTUAL MENTAL
HEALTH SUPPORT

CISION PR NEWSWIRE

**NFlection Therapeutics Announces Positive
Results from Phase 2b Study of NFX-179
Topical Gel in the Treatment of Cutaneous
Neurofibromas in Neurofibromatosis Type 1**

FOUNDRY VIRTUAL BC

YMCA MENTAL WELLNESS PROGRAMS

NIH NATIONAL LIBRARY OF MEDICINE:
CLINICALTRIALS

BODY IMAGE, SELF-ESTEEM
AND MENTAL HEALTH

CHANGING FACES: POSITIVE-THINKING
TECHNIQUES FOR PEOPLE WITH A
VISIBLE DIFFERENCE