



# **Bridging the Gap:**

**RESOURCES FOR  
RARE DISEASE  
CARE AND SUPPORT**

# INTRODUCTION

Is this booklet for me?

Rare diseases are health conditions that affect only a small percentage of the population. Despite being uncommon, they can have a big impact on your life if left undetected or untreated.

**THIS BROCHURE IS HERE TO HELP YOU UNDERSTAND WHAT RARE DISEASES ARE, AND ENCOURAGE YOU TO SEEK MEDICAL ADVICE WHEN NEEDED.**

By staying informed and paying attention to your health, you can take the right steps toward early diagnosis and prevention.

# TABLE OF CONTENTS

Introduction	2
Table of Contents	3
Basic Info About Rare Diseases	4
Seek For Professional Help	6
Living With Rare Diseases	9
Advice On Treatment	11
You Are Not Alone	13
Contact Us	15



# **BASIC INFO ABOUT RARE DISEASES**

**4-Basic Info**

# WHAT ARE

# RARE DISEASES?

A rare disease is defined as one that affects fewer than 1 in 2,000 people. There are thousands of rare diseases, and they can impact different parts of the body, including your immune system, muscles, or organs. Some rare diseases are genetic, while others develop due to unknown factors.

## EXAMPLES OF RARE DISEASES

- Cystic fibrosis
- Huntington's disease
- Muscular dystrophy
- …… etc.

It's important to understand that while these conditions are rare, early detection can make a significant difference in managing them.

# SEEK FOR PROFESSIONAL HELP

WHEN AND WHO?

# When

Sometimes, it can be difficult to know when a symptom is serious enough to see a doctor. Here are some guidelines on when to seek professional help:

- **Ongoing Symptoms:** If you've had symptoms for more than a few weeks and they haven't improved, it's time to consult a healthcare provider.
- **Sudden, Severe Symptoms:** If you experience sudden changes, like extreme pain or difficulty breathing, don't wait—get help immediately.
- **Family History of Rare Diseases:** If someone in your family has been diagnosed with a rare condition, it's a good idea to get a checkup, even if you don't have symptoms.

**Remember, doctors are there to help you. Don't hesitate to ask questions if you're unsure about your health.**

# Who

If you or someone you know is diagnosed with a rare disease, it's important to know who can help. Here's a guide to key members of a healthcare team:

Working together with these professionals can help you navigate diagnosis, treatment, and long-term care.

- **Family Doctor:** The first person to go to with health concerns. They can refer you to specialists if needed.
- **Geneticist:** Specializes in genetic conditions that may cause rare diseases.
- **Specialists:** Focuses on one certain parts of the human body, find the specialist that correspond to your rare disease.
- **Dietitian:** Can help create a nutrition plan to manage your fitness.
- **Social Worker:** Offers emotional support and connects you to societal resources.
- **Counselor or Therapist:** Helps you cope with the emotional impact of living with a rare disease and reduce the anxiety levels of your family members.

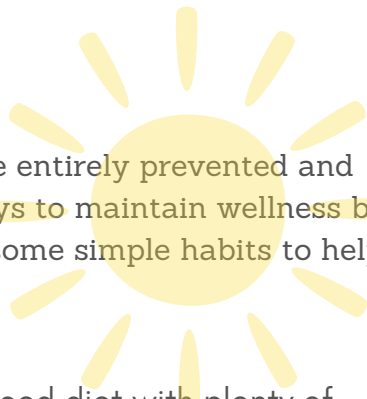
## 8-Seek For Professional Help





# LIVING WITH RARE DISEASES

**9-Living With Rare Diseases**



While rare diseases can't be entirely prevented and treated, there are many ways to maintain wellness by living with them. Here are some simple habits to help your wellbeing:

- **Healthy Eating:** A balanced diet with plenty of fruits, vegetables, and whole grains can strengthen your immune system and make you feel less fatigued.
- **Regular Exercise:** Staying active improves your overall health and can reduce the risk of some diseases.
- **Sleep and Stress Management:** Make sure you get enough sleep and learn ways to manage stress.
- **Stay Informed About Family History:** Some rare diseases are genetic, so knowing your family's medical history is essential. Share this information with your doctor if a family member has a rare condition.
- **Regular Checkups:** Even if you feel healthy, regular medical checkups can catch problems early. Don't skip these!

# ADVICE ON TREATMENT

## **Mental Health Support**

Consider speaking with a mental health professional. Coping with a rare disease can be emotionally taxing, and therapy can provide a safe space to process feelings.

## **Educate Yourself**

Knowledge is empowering. Learning about your condition and current treatments, such as targeted therapies, can help you feel more in control of your life.

## **Practice Self-Care**

Engage in activities that help you relax and recharge, such as exercising, hanging out with friends, or engaging in hobbies you enjoy.

## **Advocate for Yourself**

Be proactive in your healthcare. Keep records of your symptoms and treatments to discuss with your healthcare team. Don't hesitate to ask questions or seek second opinions.

## **Involve Family and Friends**

Keep your support network informed. Having loved ones who understand your situation can help you cope better with the difficulties in your daily life.


## **Explore Holistic Approaches**

Some people find complementary therapies, like acupuncture or nutrition counseling, helpful. Always discuss these with your healthcare provider first before participating.

## **Mindfulness and Relaxation Techniques**

Practices like yoga, meditation, or deep breathing can help manage stress and improve overall well-being.

# **12-Advice On Treatment**



**YOU ARE  
NOT  
ALONE**

**13-You Are Not Alone**

## **BC Children's Hospital and BC Cancer Agency**

- They have specialized programs and resources for rare diseases. If applicable, consult them for pediatric cases or cancer-related rare conditions.

## **Rare Disease Foundation**

- They provide resources, and advocacy for families affected by rare diseases. They may offer valuable connections to specialists and ongoing research in orphan disease.

## **Canadian Organization for Rare Disorders (CORD)**

- They advocate for people with rare diseases in Canada. They can help you find information and support networks by connecting you with local organizations in your region.

## **Genetic Services**

- BC Centre for Disease Control offers genetic counseling and testing services if the rare disease has a genetic basis. This can be crucial for diagnosis and management.

## **Clinical Trials**

- Check for ongoing clinical trials in BC. Participation can provide access to innovative therapies.

# CONTACT US

Email: [info@rarecare.org](mailto:info@rarecare.org)