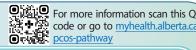
# Your Journey with Polycystic Ovary Syndrome (PCOS) For more information scan this QR code or go to myhealth.alberta.ca/pcos-pathway



PCOS is a condition that is caused by a hormonal imbalance that impacts health across the lifespan. People with PCOS may have irregular periods and have higher levels of the hormone testosterone. The ovaries may develop enlarged follicles that are often referred to as 'cysts'. You are the most important part of your healthcare team. This guide will help you to know what to expect as you work with your team to manage and treat PCOS. If you have any questions along the way, please ask your healthcare team. Click on the page numbers in blue if you want more information about the step in your journey.

#### Before your appointment (page 7)

- Write down how you feel, your symptoms, and any questions or concerns.
- Symptoms may include missed or irregular periods, acne, extra hair on the face and body, scalp hair loss, difficulty managing weight, and difficulty in getting pregnant.





Whole-person health (page 2)

# **Important Tips:** Need to connect with a primary care clinic?

ahs.ca/findadoctor

Need a translator or interpreter? Let your healthcare provider know

#### Need health advice?

Call Health Link at 811

Need to find programs and resources in your community? Call 211 or visit ab.211.ca

# Visit your healthcare provider (page 7)

- Consider bringing a family member or friend to support you. You may need more than one visit with your healthcare provider.
- Your health includes physical, emotional, spiritual, financial, and social elements.
- To better manage your health condition, your healthcare provider needs to hear from you and understand who you are and what matters to you. They will need to ask questions about your past health, family history, and menstrual cycles.

#### Get your tests (page 10)

- Your healthcare provider will do a physical exam to look for signs of PCOS, such as extra body hair, and signs of insulin resistance. They may measure your blood pressure, weight, and height.
- You will need lab tests to help with the diagnosis.
- Some people may need an internal ultrasound to view the ovaries.

# Review your test results (page 11)

- Find your test results on MyHealth Records or MyChart (myhealth.alberta.ca/myhealthrecords or ahs.ca/mychart) or ask your healthcare provider to print them for you.
- Talk with your healthcare provider so you know what your test results mean.

# Review your treatment, management & prevention options (page 12)

- Your healthcare provider will help you better understand your condition and offer you important strategies to manage your condition. This includes:
  - having a healthy eating pattern with nourishing foods

  - exercising regularly
  - managing body weight
- having healthy mental health practices
- getting restful sleep
- reducing or quitting smoking
- Some people may benefit from having medication to help with their irregular periods, extra hair growth, body weight, acne, pre-diabetes, and infertility.
- Your symptoms will need specific management such as hair removal, acne treatment, diet, sleep, or mental health supports.
- Discuss the options and decide with your healthcare provider what will work best for you.

# Talk with your healthcare provider about a referral (page 19)

• Not all patients need a referral to see a specialist. You may benefit from a referral to a different healthcare provider based on your symptoms, test results, and your history.

# Start your treatment & watch your symptoms (page 21)

- Visit your healthcare provider if you have:
  - sudden onset of new and unusual facial and body hair growth
  - development of new wide purple stretch marks



# Keep taking care of yourself (page 22)

 Keep taking care of your overall health. Look for other healthy lifestyle resources and supports.



Current as of: June 2024

## How to use this resource

The information provided in this resource is based on validated evidence from a variety of sources, including healthcare professionals in Alberta, peer-reviewed journals, current clinical guidelines, validated patient resources, and specialty care recommendations. It is intended as general health information and should not replace the clinical judgement of a qualified healthcare provider. This resource does not address the unique needs of individual patients. Always consult with your healthcare team and follow their recommendations for your specific care.

These pages are for you to use as needed. You can look through all of them at once or just the ones that help you now. Feel free to come back to the resource whenever you need it.

# Whole-person health

The whole-person health approach will help you and your healthcare team better manage your health condition. It is drawn from the teachings of the medicine wheel.

Whole-person health means thinking about all parts of your health and wellness: physical, financial and social, spiritual, and emotional. All of these parts are connected and influence each other. It's important to be aware of your personal needs in each part and to share that information with your healthcare team.



Whole-person health

- Physical: your specific health conditions and how well your body works
- **Financial and Social**: your ability to meet your housing, transportation, food, and health needs, feeling supported to manage your daily life, and having meaningful relationships
- Spiritual: your beliefs, sense of connection, and purpose
- **Emotional**: how you think, feel, and cope with life events

Whole-person health also reminds us that we are all connected and work together: you, your support systems, and your healthcare providers. Your healthcare providers could be your doctor, nurse practitioner, or a team that comes together with you to plan and organize your care.

Your healthcare provider needs to understand who you are and what matters to you. This helps to build trust. But it can be hard to know what to share or what to say. Try starting by asking yourself:

"What are the things in my life that are important to me?"

"What are the things in my life that may be affecting my health and well-being?"



Bringing forward what matters to you is important. Here are some examples of things you may want to talk about with your healthcare provider:

#### **Physical**

"My weight is making it hard for me to exercise. I need support with my nutrition."

"Because of my symptoms, it's hard to take care of myself."

"My hair growth is so much that I need to shave every day."

#### Financial and Social

"I feel I can't go out as my acne and body hair is embarrassing."

"I need my daughter with me as a translator."

"I would like to get laser hair removal but can't afford it."

#### Mental and Emotional

"I feel anxious."

"I am struggling to get out of bed in the morning."

"I feel I have no control. I feel no matter what I do I can't lose weight."

"I feel I have no support. How do I access professional support other than my family doctor?"

#### Spiritual

"It's important that my values and beliefs are considered in my care."

"How can I include my culture's foods and family recipes in my nutrition plan?"

"It's important that my religious practice of fasting is respected and brought into my care."

# What is PCOS?

PCOS is a disorder of hormonal imbalance that can affect your period and your overall health. PCOS is a common condition that affects 10-15% of people with ovaries and impacts health across the lifespan. The hormone imbalance causes the ovaries to produce excess of a hormone called testosterone.

#### Extra testosterone may cause:

- missed or irregular periods
- severe acne
- darker patches of skin on parts of the body such as the armpits, neck, or groin area (acanthosis nigricans)
- extra hair growth on the face and other parts of the body (hirsutism)
- scalp (head) hair loss
- weight gain
- difficulty getting pregnant



Image of extra hair on the face (hirsutism).

 ${\it Source: } \ @\ 2014, Iranian\ Red\ Crescent\ Medical\ Journal;\ Published\ by\ Kowsar\ Corp.\ https://openi.nlm.nih.gov/gridquery?q=hirsutism&it=xg&m=1&n=100$ 



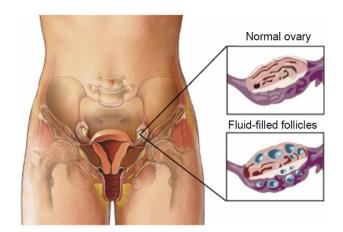
Image of darkening of the skin on the neck (acanthosis nigricans).

Source: © Indian Dermatology Online Journal. <a href="https://openi.nlm.nih.gov/gridquery?q=acanthosis">https://openi.nlm.nih.gov/gridquery?q=acanthosis</a> nigricans&it=xg&m=1&n=100

The ovary is an organ in the pelvis.

The ovaries produce hormones including estrogen and testosterone. They contain follicles which release an egg during ovulation.

In those with PCOS, follicles do not fully mature, but instead fill with fluid. These fluid-filled follicles then appear to look like cysts.



Source: used with permission. onlinelibrary-wileycom.login.ezproxy.library.ualberta.ca/doi/full/10.1016/j.jmwh.2010.04.005

#### What causes PCOS?

It is caused by hormones that are out of balance. What causes the hormonal imbalance is not fully understood.

#### **Contributing Factors**

- The ovaries may produce abnormally high levels of testosterone, which can cause missed, or irregular periods and disrupt ovulation.
- **Heredity:** Research shows that PCOS runs in the family. People who have a family history of PCOS, type 2 diabetes (a condition in which you have too much glucose in your blood) or gestational diabetes (high blood glucose that is first diagnosed and only occurs during pregnancy) are at higher risk of developing PCOS themselves.
- Insulin resistance: Insulin is a hormone that helps your body use sugar (glucose). Insulin helps glucose enter the body's cells where it is used for energy. Insulin resistance happens when the body is unable to use insulin properly. If the body's tissues don't respond to insulin properly, glucose can't enter the cells. This causes the pancreas to make more insulin and blood insulin levels to rise to help glucose enter the cells for use. This causes type 2 diabetes. Extra body weight can cause insulin resistance.

#### **Symptoms of PCOS**

#### Common symptoms you may have with PCOS are:

- missed periods, irregular periods, and very light periods (including spotting)
- extra hair on the face or body
- thinning hair on the head
- acne
- difficulty managing weight (weight gain or difficulty losing weight)
- difficulty getting pregnant
- darkening of skin on the neck, armpits, or groin area

#### You may also have symptoms of:

- sleep apnea (heavy snoring or breathing that stops for short periods during sleep)
- fatigue (feeling of tiredness, exhaustion, or lack of energy)
- anxiety, depression, and mood changes

#### If you have PCOS, tests might also show:

- High blood pressure (high blood pressure doesn't usually cause symptoms. Most people
  don't know they have it until they get their blood pressure checked. However, very high
  blood pressure can cause severe headaches and vision problems).
- High blood glucose (many people do not know they have high blood glucose until they
  get it checked. If blood glucose is high, you may experience increased thirst, increased
  urination, weight loss, frequent bladder infections, frequent yeast infections, lightheadedness, and fatigue).
- High blood lipids, such as cholesterol and triglycerides (high blood lipids do not usually
  cause symptoms in most people. It is usually found during a blood test. However, high
  blood lipids in some people can cause hardening and blockage of blood vessels called
  heart and vascular disease. This can decrease blood flow to the heart causing a heart
  attack or to the brain to cause a stroke).

#### What should I watch for?

#### Contact your healthcare provider if you have:

- Sudden onset of new and unusual hair growth on your face or body
- Development of new wide purple stretch marks on your body



#### Before your appointment

Here are a few tips to help you get ready for your appointment with your healthcare provider.

- Consider using a symptom tracker to write down important information to share with your healthcare provider about your symptoms.
- A symptom tracker can help you remember what symptoms you're feeling, when it started, how often it happens, and what makes it better or worse.
- Write down a list of your questions and concerns. When you're done, read your list and mark the most important things.
- Make a list of the prescription and non-prescription (over the counter) medicines you use, including any vitamins, herbs, and supplements.
- Ask someone you trust to go with you to your appointment. They can help you ask questions, write down instructions, and remember explanations.



# Helpful tools and resources

To get the most out of your visit, plan to write notes during the visit or see the Alberta Health Services My Care Conversations app (<a href="mailto:ahs.ca/careapp">ahs.ca/careapp</a>) website for more information about recording your conversation with your healthcare provider.

Use a symptom tracker: <a href="hqa.ca/symptom-tracker">hqa.ca/symptom-tracker</a> (Health Quality Alberta)

#### **During your appointment**

Your healthcare provider may ask you several questions about you and your family's health history. These questions help your healthcare provider make a diagnosis of PCOS and know how to best support your health and wellness.

Questions your healthcare provider may ask:

- When was your very first period, when was your last period, and how long is your usual menstrual cycle
- If you used any medication to control your period
- If you have been pregnant, tried to get pregnant or have had any miscarriages
- If you have been experiencing acne, particularly that which is not responding to usual treatments
- If you have had unwanted hair growth and if you have been using any hair removal treatments

- Your ethnicity
- If you have experienced hair loss
- If you have been having issues managing your weight
- If you have been diagnosed with prediabetes, diabetes, or high cholesterol and triglycerides
- If you have people in your family who have had PCOS, diabetes, gestational diabetes, miscarriages, or fertility problems
- What medications or supplements you are taking

#### Healthcare provider's assessment

#### Height, weight, and blood pressure:

Why do I need this assessment?

- PCOS can increase your risk for diabetes and heart disease.
- Having extra body weight and high blood pressure may also increase the risk of these conditions.
- Knowing your current height, weight, and blood pressure will help your healthcare team manage these risk factors for diabetes and heart disease, in addition to your PCOS symptoms.
- You may have tests and assessments to help with the diagnosis of PCOS and to rule out other health problems.

#### What is weight bias?

Weight bias refers to personal attitudes and beliefs about people with larger bodies.

Weight stigma refers to social stereotypes and misconceptions about people with larger bodies. Weight bias and stigma can lead to weight discrimination.

If you experience weight bias in your care, resources like <u>Weight Bias - Obesity Canada</u> can support you.

#### Exam to assess for signs of high testosterone levels, insulin resistance and other conditions:

#### What should I expect?

- With your consent, your healthcare provider may ask you to put on a medical exam gown.
- Your healthcare provider may look for skin tags and dark, thick velvety skin in body folds and creases. This is called acanthosis nigricans and is typically seen in the back of the neck.
- Your healthcare provider may look for extra hair in different parts of the body, especially on your face and chin. You may want to delay doing any hair removal before you see your healthcare team.
- Your healthcare provider may look for wide purple stretch marks in your belly area and other parts of the body.

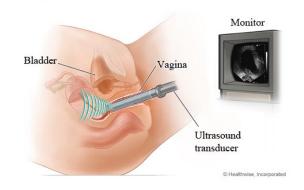
#### **Blood tests**

- There are several different blood tests that may be done to understand your different hormone levels. Hormones control the activity of different cells and organs in your body. Problems can happen when your hormone levels are out of balance.
- Your healthcare provider may ask you to have these blood tests done at a certain time in
  your menstrual cycle. Hormone levels vary during the menstrual cycle, and it is
  important to make sure that the tests are done at the right time so your healthcare
  provider has a good understanding of what is happening with your hormones at key
  times of the cycle.
- Once you have a confirmed PCOS diagnosis or during the assessment of your PCOS, you may also get blood tests to help determine certain risk factors for other medical conditions associated with PCOS, like diabetes and vascular disease. These blood tests include:
  - Oral glucose tolerance test (OGTT). This measures glucose levels in response to a glucose drink and the body's ability to use the glucose. If the body cannot use glucose well it can lead to insulin resistance and diabetes.
  - Blood lipid panel. You can learn more about cholesterol and triglycerides here:
     <u>Cholesterol and Triglycerides Tests (alberta.ca).</u>

#### Ultrasound

- Only some people may need this investigation to confirm a diagnosis of PCOS.
- For some patients, a transvaginal ultrasound may be needed with your consent to view your ovaries and confirm the diagnosis of PCOS.
- The ultrasound checks your ovaries for enlarged fluid filled follicles and checks the thickness of the lining of your uterus.
- A wand-like device (transducer) is placed in your vagina. The transducer sends sound waves that are turned into images on a computer screen.

#### Transvaginal Ultrasound



It is important to know what your test results are and what they mean for you personally. Take time to discuss your results with your healthcare provider. Medical terms can be hard to understand. And even common words like "positive" or "negative" might mean something different for medical tests. Ask your healthcare provider for explanations and examples to make sure you fully understand.

#### You might ask:

"What does this mean for me and what is my next step?"

"Is there a current concern? If so, what is it?"



#### **Diagnosis of PCOS**

A diagnosis of PCOS can be made when at least 2 of the following 3 criteria are met. (Not all three criteria are required for the diagnosis of PCOS):

- Hyperandrogenism: This may include higher levels of testosterone as shown in the blood tests you would have completed, and/or physical signs of excess testosterone.
   Physical signs may include acne, scalp hair loss, and hirsutism (excess hair growth on the body or face).
- Menstrual irregularities: Having irregular periods, long gaps between periods, missed period or no periods.
- Polycystic ovaries: Ultrasound findings may show multiple fluid filled follicles that look like cysts.



# Helpful tools and resources

You may find some of your results and health information using secure online tools:

#### MyHealth Records

See your lab results, immunizations, and some other results with a MyHealth Records account. Sign up at <a href="mailto:myhealth.alberta.ca/myhealthrecords">myhealth.alberta.ca/myhealthrecords</a>.

#### **MyChart**

See your health information, manage your Alberta Health Services appointments, and interact directly with some members of your healthcare team. Ask your healthcare provider how to access your MyChart account. Learn more at <a href="mailto:ahs.ca/mychart">ahs.ca/mychart</a>.



# Review your treatment, management, and prevention options

Everyone needs their own treatment and management plan. Your treatment choices will depend on your history, symptoms, risk factors and what is important to you. You and your healthcare provider will discuss what options are available. You know your health best.

You can participate fully as a member of the care team by:

- asking questions
- sharing your healthcare goals
- sharing how you want your chosen support persons involved

AHS has implemented Shared Commitments, which is an initiative designed to improve the healthcare experience of Albertans by engaging them in their own care and building strong relationships with care providers. Learn more at <a href="Shared Commitments">Shared Commitments</a> | Alberta Health Services (ahs.ca/shcm/Page18499.aspx).

#### What should I share with my healthcare provider?

- What has worked for you in the past to manage your current condition?
- What types of things help you work better with your healthcare team and what do you expect and need from the relationship with your healthcare provider?
- What impact the health condition or issue is having on things that are important to you, like your job, hobbies and interests, and relationships?

It's important to talk about these things with your healthcare provider because they all play a role in your health and well-being.

#### You are the most important part of your healthcare team.

If you don't understand what your healthcare team is telling you, let them know right away. Be open and honest. You might say:

"This is new to me. Could you please explain it slowly, using language that is easier to understand?"

"It sounded like you said that I should... Did I understand that correctly?"



#### Lifestyle Management

A healthy eating pattern with nutritious foods and regular physical activity are key strategies for managing PCOS in any stage of life. Addressing these areas can help with improved quality of life and prevention of long-term health problems.

#### Nutrition

- A healthy eating pattern with nutritious foods that meets your energy and nutrient needs and is sustainable for the long term is recommended. Eat a variety of healthy foods each day to meet your energy needs as guided by 'Eat Well Live Well' <a href="Canada's Food Guide">Canada Canada C
  - o Eat whole foods rather than processed foods.
  - Eat fresh or frozen vegetables and fruit.
  - o Eat protein rich foods (lean meats and plant proteins like lentil, soy and tofu).
  - Eat whole grain foods.
  - Reduce foods that are high in sugar, salt and saturated fats.
  - Make water your main drink.
- There is no single approach to healthy eating that works to improve symptoms of PCOS.
- You can find accurate and reliable nutrition information on how to <u>Choose & Prepare</u> Healthy Food | Alberta Health Services.



- All patients with PCOS can benefit from nutrition counselling. Your healthcare provider
  may recommend that you see a registered dietitian for this counselling. Registered
  dietitians play an important role in helping you achieve your best nutritional health.
- Dietitians provide services in many settings, including primary care networks (PCN's), clinics, community health centers, specialty clinics and private practice. There are many ways to access a Registered Dietitian, so it is important to discuss your specific needs with your healthcare provider to determine the best route.

In most cases, a **Registered Dietitian** can complete a nutrition assessment and help you understand your specific nutritional needs. They can provide nutritional counselling, behavioral modification support, resources, and tools.

- If you have a general nutrition question, call 811 and ask to speak with a Dietitian or complete the <u>self-referral form</u>.
- Workshops, classes, and services from the Alberta Healthy Living Program can help you to improve your health and nutrition education. Different classes and workshops can be found here: <a href="mailto:ahs.ca/ahlp.">ahs.ca/ahlp.</a>
- For some patients, there may be challenges with having enough money for food or you
  may struggle to find healthy food. Here are some resources that can help you explore
  options for spending less money on food and accessing healthy food:

Call, text, or chat with <u>211 Alberta</u> to find out about financial benefits, programs, and services.

- o Tips to Spend Less Money on Food (albertahealthservices.ca)
- o Learning About Food Insecurity: Not having enough money for food (alberta.ca)

#### Physical activity

- Make physical activity a regular part of your life.
- The <u>Adults 18-64 24-Hour Movement Guidelines (csepguidelines.ca)</u> give recommendations for physical activity, and your healthcare provider may recommend some specific exercises for you to start with. Always consult your healthcare provider before starting a new activity program.
- For the prevention of weight gain and maintenance of health, adults (18-64 years) should aim for 150 to 300 minutes of moderate-intensity activities or 75 to 150 minutes of vigorous-intensity aerobic activity per week or an equivalent combination of both spread throughout the week, plus muscle strengthening activities (for example resistance/flexibility) on two non-consecutive days per week.
- Choose physical activities that are enjoyable for you.
- Move at every opportunity. Some ideas are taking the stairs, parking further away, sitting less, and walking whenever possible.
- You can look here for more ways to improve your <u>Fitness: Getting and Staying Active</u> (alberta.ca).

#### Weight and health

Work towards staying at a healthy weight and/or maintaining healthy weight. This is the
weight at which you feel good about yourself, have energy for work and play, and can

- manage your PCOS symptoms, and prevent and manage other conditions such as diabetes and heart disease.
- Healthy eating patterns, nutritious foods and physical activity can help you achieve your best weight and lower your pre-diabetes and heart disease risk.
- Losing weight can be hard as there are many factors that impact body weight. If you carry extra weight, losing weight may help to improve PCOS symptoms.
  - o It is important to have realistic expectations when starting your weight and health journey. Healthy bodies come in all shapes and sizes. It is important that you set achievable and sustainable goals that you can adhere to long term.
  - o Some helpful resources to help you manage your weight:
    - Weight management resource tool kit (alberta.ca)
    - Your Best Health: Adult Weight Management (alberta.ca)
    - Eating Well for Weight and Health (albertahealthservices.ca)
    - Check on Your Eating Habits (albertahealthservices.ca)
    - Explore Your Relationship with Food (albertahealthservices.ca)

#### **Smoking**

• If you smoke, think about reducing or quitting. This can be challenging, so talk to your healthcare provider about stop-smoking programs or visit <a href="Tobacco">Tobacco</a>, <a href="Vaping & Cannabis Program | Alberta Health Services">Alberta Health Services</a>. These can increase your chances of quitting for good.

#### Medications

- To manage your unwanted hair growth, menstrual regulation, body weight and diabetes risk your healthcare provider may recommend hormone treatment such as contraceptive pills, medications that block the action of testosterone, or metformin (which helps regulate blood glucose).
- At times injectable medications are used to help with weight loss. At times over the counter supplements may be used in people with PCOS. Make sure to have an open and honest conversation with your healthcare team about what matters to you.
- Your healthcare team may discuss medications to address your specific needs and risk factors for conditions associated with PCOS.

#### Supplements

- Nutrient-rich foods and dietary supplements may be recommended by your healthcare team if a nutrient deficiency is found in your blood.
  - Currently, there is limited evidence to support recommendations for specific supplements for PCOS symptoms.

- Here is a helpful resource on <u>Making Sense of Supplements.</u>
- Vitamin D is recommended for all Albertan's and a multivitamin with folic acid is recommended for women of child-bearing age.
- o If you are planning to become pregnant, you should start taking prenatal vitamins with folic acid.
- It is recommended that all supplements are used in consultation with your healthcare provider (family physician, pharmacist, or other specialists on your healthcare team).

#### **Symptom Management**

#### Period irregularity

- Healthy eating patterns, good sleep patterns, physical activity, and weight management may improve period irregularity and your ability to ovulate.
- Medications to better regulate hormones can be prescribed to improve period irregularity.
- Although evidence is limited you may want to try other nutritional supplements to help regulate periods. These can be discussed with your healthcare provider.

#### Unwanted hair growth (called hirsutism)

- Areas affected by excess hair growth may include the face, arms, legs, back, chest and abdomen.
- For existing excess hair, there are multiple hair removal methods, such as shaving, plucking, laser hair removal, electrolysis, or epilation. These differ in cost and long-term effectiveness. Before trying one, ask your healthcare provider about what may work best for you, risks of infection and scarring.
- There are hormone medications that can be used in discussion with your healthcare provider to help your hormone balance to improve and prevent excess hair growth. You can talk to your healthcare provider about these options and what is best for you.

#### Acne

- Acne treatment may include non-prescription or prescription medicines that you put on your skin (topical) or take by mouth (oral).
- A healthy diet, maintaining a healthy weight and being active can also help manage your acne.

#### **Fertility**

- If you have PCOS, you may have difficulty in getting pregnant.
- It is important to discuss your pregnancy plans with your healthcare team and determine together what might be the best options for your pregnancy planning.
- You may need a referral to a fertility specialist from your healthcare provider.
- Being active, losing weight or maintaining a healthy weight, and good nutrition can have positive impacts on your fertility. Even a modest weight loss may help improve ovulation.
- It is also important to have healthy weight, normal glucose, and normal blood pressure before becoming pregnant.

#### Managing other conditions that are associated with PCOS

#### Mental health, Emotional well-being, and Quality of life in PCOS

- Mental health and quality of life can be a big concern for you due to physical symptoms, hormones, challenges with fertility, body image and long-term medical health concerns.
- It is important to be aware and access for your pre-existing mental health conditions or any undiagnosed mental health conditions.
- You may have increased chances of depression, anxiety, eating disorders and you may experience emotional challenges such as mood changes, distress, and low self-esteem.
- In some cases, you may benefit from seeing a registered psychologist or a mental health practitioner.
- Reliable resources can be found here: <u>Help in Tough Times</u> | <u>Alberta Health Services</u>.

#### Sleep apnea

• If you have PCOS, you may be at risk for sleep disorders or **sleep apnea**. The breathing stops for short periods during sleep in people with these conditions. When you stop breathing or have reduced airflow into your lungs during sleep, you don't sleep well, and you can be very tired during the day. This can also increase insulin resistance. If you have signs of sleep apnea which include snoring, waking unrefreshed from sleep, daytime sleepiness, or fatigue talk with your healthcare provider. You may need a sleep study and other tests.

#### **Diabetes**

- You may be at risk of developing diabetes due to insulin resistance that is associated with PCOS.
- Aside from dietary and lifestyle changes, your provider may discuss medications that can help improve blood sugar control.

#### Obesity

• You may be predisposed to increased weight gain and obesity due to the metabolic and hormonal issues that are associated with PCOS, such as insulin resistance and high testosterone levels. Obesity in turn can exacerbate the symptoms and metabolic complications of PCOS (diabetes, high blood pressure, menstrual irregularity, difficulty to become pregnant and increased complication of pregnancy).

#### Heart and blood vessel disease

- People living with PCOS may be at increased risk of heart and blood vessel disease in which blood vessels thicken and harden, and fatty deposits called plaque, can build up. These can cause blockage in blood vessels that supply blood and oxygen to your heart muscle, brain, other organs, and limbs.
  - o This process of plaque buildup and hardening of blood vessels, is called atherosclerosis and can block blood flowing through blood vessels.
- It is important that you and your healthcare provider monitor your risk factors for cardiovascular disease, including your blood pressure and lipids.

#### **Pregnancy complications**

- If you are planning to become pregnant, you may be at risk developing:
  - Gestational diabetes (high blood sugar that is first and only diagnosed during pregnancy). Gestational diabetes may affect your baby. You may need to use insulin to keep your glucose normal and your baby safe during pregnancy.
  - o If you have high blood pressure during pregnancy, you may need medications that are safe for you and your baby. High blood pressure during pregnancy that causes increased protein in your urine is called pre-eclampsia.

#### **Endometrial hyperplasia**

 A problem with the uterus due to excess estrogen, where the lining (endometrium) of the uterus gets too thick. This can cause abnormal uterine bleeding and may lead to endometrial cancer. Consider other lifestyle skills such as goal setting, self-monitoring, problem solving, assertiveness training, and reinforcing changes and relapse prevention. There are many different types of healthcare providers who can help you gain these important skills and achieve your health goals.

Asking the following questions can help you make an informed decision about your different treatment options and decide which one(s) will work best for you:

"What are the advantages and disadvantages of each treatment/management option?"

"Can I use any of these treatment/ management options together?"

"How will this treatment/ management make me feel? Will it have side effects?"

"What results can I expect?





# Talk with your healthcare provider about whether a referral is needed

Not all patients with PCOS need a referral. In most circumstances your primary care provider (like a family physician or nurse practitioner) can support you in managing your PCOS without complications. You may need multiple appointments to manage your PCOS symptoms and other associated health concerns. The need for a referral to other healthcare providers will depend on the severity of your symptoms, and your test results.

#### Registered dietitian

 A registered dietitian assists patients to make nutrition changes to manage their medical condition through nutritional counselling. A dietitian helps people achieve healthier diets and eating habits to prevent and treat chronic diseases.

#### **Endocrinologist**

 A medical doctor who specializes in diagnosing and treating health conditions related to hormones and hormonal glands. An endocrinologist can help manage your period, extra hair growth, weight management, diabetes, and other hormonal conditions

#### **Gynecologist**

A gynecologist is a medical doctor who specializes in diagnosing and treating issues
with the female reproductive organs (the vulva, vagina, uterus, and ovaries). A
gynecologist can help with any issues related to menstruation and fertility.

#### **Dermatologist**

 A dermatologist is a medical doctor who specializes in diagnosing and treating diseases and concerns of the skin, hair, and nails. A dermatologist can help with management of acne, excessive hair growth and other skin changes.

#### Psychologist or psychiatrist

 Psychologists and psychiatrists study how we think, feel, and behave from a scientific viewpoint and apply this knowledge to help people understand, explain, and change their behavior. Psychotherapy can provide valuable support and guidance to people with PCOS, to help with the emotional challenges and behaviour-lifestyle changes and to enhance overall health and well-being.

#### **Pharmacist**

 A pharmacist is a health-care professional who is licensed to support patients with their medications. A pharmacist can monitor medication interactions, and counseling patients regarding the effects and proper use of medications.



# Helpful tools and resources

To learn about how to prepare for your specialist appointment, check out the QuRE Patient and Caregiver Journal by visiting <a href="mailto:ahs.ca/qure.">ahs.ca/qure.</a>



# Start your treatment & watch your symptoms

As you try the treatment options you chose, remember that if something doesn't work the way you thought it would, think about other options and connect with your healthcare provider to find a treatment that will work for you.

Remember, symptoms and signs of PCOS can overlap with those of other medical conditions.

#### Contact your healthcare provider if you develop:

- Sudden onset of new and excessive hair growth on your face or body
- New wide purple stretch marks on your body

Watching your symptoms is important. Call your healthcare provider or Health Link at 811 if you have any concerns. You might feel like you don't want to bother your healthcare team, but no detail is too small to share. If it matters to you, it will matter to your healthcare team.

You can clarify with your healthcare team what to expect in terms of follow-up communication. Connect with your healthcare team whenever you:

- Have questions
- Notice your symptoms getting worse
- Have problems with your medicine
- Haven't gotten test results or heard back about an appointment in the time you had agreed to



# Helpful tools and resources

If you can't reach your healthcare provider and need health advice or information, call Health Link anytime, day or night, by dialing **811**.

There are many different things that can impact your health and wellness. It is important to be able to work with your healthcare team to decide what is best for you given your own unique circumstances as you manage your PCOS. Remember, you don't need to do everything all at once.

Take realistic and manageable steps in your health and wellness. Consider why making a change may benefit you and the things that matter to you.



# Helpful tools and resources

#### Find programs and resources in your community:

211 connects Albertans to the programs and resources they need, anytime, day or night. Whether you're looking for help with mental health, financial assistance, basic needs or other challenges, 211 is here to help you find supports. It's free, confidential, and available in over 170 languages by phone, making it easy to access help when you need it. To connect with **211 Alberta**:

- Call 211
- Text INFO to 211
- Chat or search at ab.211.ca

The **Alberta Healthy Living Program** offers free workshops, classes, and supervised exercise and nutrition services to adults living with a variety of chronic conditions and diseases. Many education classes and workshops are available province wide. Learn more by visiting <a href="mailto:ahs.ca/ahlp">ahs.ca/ahlp</a>.

Chronic Disease Management support: <a href="mailto:ahs.ca/cdm">ahs.ca/cdm</a>

Health information & tools: <a href="mailto:myhealth.alberta.ca/Pages/HealthInfoToolsDefault.aspx">myhealth.alberta.ca/Pages/HealthInfoToolsDefault.aspx</a>

## Resources

There's lots of information out there, and it can be confusing to know what information is accurate and true. Here are some great resources that may be helpful for you.

- PCOS.Together (ualberta.ca)
- PCOS and You (ae-society.org)

#### Get help now:

Emergency: Call 911Health Link: Call 811

#### Mental health, addiction, and crisis support:

Addiction Helpline: 1-866-332-2322

Mental Health Helpline: 1-877-303-2642

Crisis Text Line: Text CONNECT to 741741

• Crisis Services Canada: 988, or visit talksuicide.ca

## Helpful tip

If you can't print this resource at home, ask a family member, friend, or your healthcare provider to print it for you. You can also use a computer and printer at your local library.

#### Community and social supports:

- Alberta 211: 211, or visit <u>ab.211.ca</u>
- Family Violence Info Line: 310-1818, or visit <u>alberta.ca/family-violence-find-supports.aspx</u>
- Income Support: 1-866-644-5135, or visit <u>alberta.ca/income-support.aspx</u>

#### Alberta Health Services programs:

- Home Care: ahs.ca/homecare
- Find a Dietitian: <a href="mailto:ahs.ca/nutrition"><u>ahs.ca/nutrition</u></a>
  - Health Link has dietitians to answer nutrition questions. Call Health Link at 811 and ask to talk to a dietitian or complete the self-referral form on ahs.ca/811.
- Spiritual Care Services: <u>ahs.ca/spiritualcare</u>

#### Primary care (family doctors):

- Find a doctor or nurse practitioner: <u>ahs.ca/findadoctor</u>
- Virtual care guide: <a href="mailto:ahs.ca/virtualhealth">ahs.ca/virtualhealth</a>

#### Patient concerns and feedback:

- Office of Alberta Health Advocates: <u>alberta.ca/office-of-alberta-health-advocates.aspx</u>
  - Offers coaching to help you advocate for yourself in the health system, and supports learning how the health system works and how to navigate through it.
- Alberta Health Services Patient Relations: 1-855-550-2555, or visit <a href="https://doi.org/abs/nct/abs/abs/abs/2007/2015">ahs.ca/patientfeedback</a>

# Name or clinic name: Phone number: Name or clinic name: Phone number: Name or clinic name: Phone number:

# Notes

Use this space to take notes.

Phone number:

# Background

#### **About this Pathway**

The AHS Provincial Pathways Unit co- developed this patient pathway in partnership with patient and family advisors, primary and specialty care providers in Alberta. It is current as of **June 2024.** 

#### Authors & Conflict of Interest Declaration

This pathway was reviewed and revised by a multi-disciplinary co-design team including endocrinologists, gynecologists, primary care providers and patient partners from across Alberta.

#### **Pathway Review Process**

Primary care pathways undergo scheduled review every three years, or earlier if there is a clinically significant change in knowledge or practice. The next scheduled review is June 2027. However, we welcome feedback at any time. Please send your <u>feedback here</u>, or email us at <u>albertapathways@primarycarealberta.ca</u>.

#### **Copyright Information**

This work is licensed under a Creative Commons Attribution-NonCommercial-Share Alike 4.0 International license. You are free to copy, distribute, and adapt the work for non-commercial purposes, as long as you attribute the work to Primary Care Alberta and abide by the other license terms. If you alter, transform, or build upon this work, you may distribute the resulting work only under the same, similar, or compatible license. The license does not apply to content for which Primary Care Alberta is not the copyright owner.

#### Disclaimer

This pathway represents evidence-based best practice but does not override the individual responsibility of healthcare professionals to make decisions appropriate to their patients using their own clinical judgment given their patients' specific clinical conditions, in consultation with patients/alternate decision makers. The pathway is not a substitute for clinical judgment or advice of a qualified healthcare professional. It is expected that all users will seek advice of other appropriately qualified and regulated healthcare providers with any issues transcending their specific knowledge, scope of regulated practice or professional competence.