

# No Period.

## Now What?

A Guide to Regaining Your Cycles  
and Improving Your Fertility

CHAPTER 6

PCOS OR

HYPOTHALAMIC AMENORRHEA



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*with* **Stephanie G. Buckler, Esq. & Lisa Sanfilippo Waddell**

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We would like to thank [Kate Albarella RD, LDN](#) for reviewing and providing feedback on this chapter. She is a dietitian who works with women with PCOS; if you find that you DO have PCOS, please consider working with her. [TheDietitianKate@gmail.com](mailto:TheDietitianKate@gmail.com)

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Published 2018.

First edition published 2016.

Cover design by Mallory Blondin

1. Health and Fitness--Women's Health. 2. Health and Fitness--Infertility.

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## 6

# The HA/PCOS Conundrum

WHEN WE TELL our doctors we're not getting our periods, there's a diagnostic path they follow to determine the cause ([chapter 4, "Diagnosis"](#)). This includes a verbal history, a physical exam, some hormonal assessments, and perhaps an ultrasound to look at our ovaries and uterus. Based on these findings, they propose a diagnosis. Often, that diagnosis is hypothalamic amenorrhea (HA). However, there is another condition, called polycystic ovarian syndrome (PCOS) that affects around 12% to 18% of the population<sup>1</sup> and manifests similarly to HA in some cases. So it is natural for this to be among the conditions suggested when we visit the doctor complaining of a missing period.

In this chapter, we talk about how to correctly diagnose PCOS and/or HA, as well as some treatments and long-term issues to think about if you do in fact have PCOS. If you're not interested in reading through all the research and just want the short version, here it is: it is common for doctors to diagnose PCOS based on the presence of amenorrhea and an ovarian ultrasound showing lots of small follicles (egg-containing structures called "cysts"). BUT, this information is not sufficient to diagnose PCOS **over** HA, especially when the risk factors for HA are present<sup>2</sup>, as discussed in [Part 1, "Hypothalamic Amenorrhea Nuts and Bolts."](#) If you've been told you have PCOS, please ask some more questions and make sure that it is the correct diagnosis for you.

*Kelli:* Where do I begin? Let me keep this to the point: you know yourself best. You know best what you have done to yourself, regardless of

your diagnosis. Have you been restrictive with food? Have you overdone working out? Were you ever at a low weight or lost weight quickly by creating a severe calorie imbalance? The thing is, we HAers will be told many things. I have been diagnosed with PCOS by one doc, HA by two others, and with thyroid dysfunction by another. All reproductive endocrinologists. All correct to a degree. Yes, my ovaries are polycystic. WHY? Because the eggs I have are not getting released so they just hang around. Yes, my thyroid hormones are abnormal, but when I dig deeper into the results, I realize it is my T3 that is low—the marker of “illness” and “starvation”—so no, I don’t have thyroid disease. I caused my hypothalamus to slow down my metabolism to keep me alive, and also to shut down reproduction. Could I believe I have PCOS, take fertility meds and metformin, which lowers sugar, and continue working out like a psycho and eating low carb? Yes, I could. I would love to believe that and continue in my destructive ways ... but in the end I know the truth. I under-ate and worked out every day. I lost weight, was too lean for my body, and lost my periods.

## What Is PCOS?

PCOS is a condition in which a woman’s hormones are out of balance. There are a number of ways in which PCOS manifests, and any given person with PCOS can exhibit a different cluster of symptoms. Some issues that are common with PCOS, and the symptoms they elicit, include:

- An excess of “male” hormones like testosterone—leading to unwanted physical side effects like male pattern hair growth (hirsutism) and acne.
- Insulin resistance—the body does not respond appropriately when the hormone insulin is produced to help process sugar (glucose). This leads to more insulin being made to try and overcome this resistance. The continued overproduction can lead to diabetes over time if left untreated.
- Issues with ovulation—abnormal levels of androgens can work to prevent timely release of an egg and lead to issues with fertility.

PCOS is often thought of as a condition associated with being in a larger body because the hormonal imbalances can make it easy to gain and difficult to lose weight. But, about a third of PCOS cases are found in women with a BMI <25<sup>3</sup>. This is sometimes called “lean” or “thin” PCOS, but it’s not a different condition and the diagnostic procedures don’t vary. The

distinction is only based on body size which may be due to the degree of hormonal imbalance, in turn associated with the degree of long-term concerns; see the “[Long-Term Concerns with PCOS](#)” section.

## Diagnosing PCOS

Over recent decades there have been a number of attempts to develop standardized criteria for diagnosing PCOS to include all the varied manifestations. The current gold standard was agreed to by the members of a consensus workshop held at the National Institutes of Health (NIH)<sup>4</sup>, and originally put forth by a group of experts in the field<sup>5</sup>. They are often called the “Rotterdam” criteria because the workshop was held in Rotterdam, Netherlands. In order to be diagnosed with PCOS by these criteria, a woman needs to exhibit two out of three of the following<sup>6</sup>:

- 1) Polycystic ovaries viewed on ultrasound (P)
- 2) Oligomenorrhea (long periods of time between menstruation) or amenorrhea (no menstruation) (O)
- 3) Hyperandrogenism (excess androgens) (H)

First, to diagnose polycystic ovaries, a transvaginal ultrasound should be performed. The machine needs to be able to scan at 6 MHz (megahertz) or greater in order to properly visualize the small follicles (2 mm to 9 mm) that need to be counted. Doctors who specialize in PCOS are clear that it is not sufficient to take a quick look at a woman’s ovaries, see a lot of follicles, and say the ovaries are polycystic<sup>7</sup>. The most recent criteria require more than 25 follicles between 2 mm and 9 mm to be present in each ovary, and/or the ovarian volume (three-dimensional area) must be greater than 10 mL<sup>8</sup>. In PCOS, the follicles are often lined up at the edge of the ovary with a “string of pearls” appearance, although this is not always the case and is not required for the diagnosis.

*Steph:* When I went for my first ultrasound, the ultrasound technician told me I had polycystic ovaries. I immediately asked her if that meant I had PCOS. She said no, not at all. She told me, “Many women, about 30%, have the appearance of polycystic ovaries but that does not mean they have PCOS.”

Second, diagnosing missing or infrequent periods is the easy part; that is just based on a verbal history from you. A missing period is obvious—you just don’t bleed. With PCOS, periods can occasionally be normal, but more

commonly cycles are either irregular (coming at varied intervals), and/or infrequent (more than 35 days in between periods). However, if it's a question of PCOS versus HA, you're obviously coming to the doctor with absent periods.

Finally, diagnosing hyperandrogenism. This gets a little trickier as not all androgens will necessarily be elevated when one has PCOS, and the tests were created for men, so measurements in the range appropriate for women are less accurate. Below, we show some of the hormones (including androgens) that might be tested, along with results that commonly point to PCOS. The more severe the PCOS, the more hormones are elevated, and to a higher degree.

### Hormonal levels in PCOS

Hormone	Normal result*	Expected value with PCOS
FSH	3.0–20.0 IU/L	Low-normal to normal
LH	2.0–5.0 IU/L	Normal to high-normal (greater than FSH)
Estradiol (E <sub>2</sub> )	20–150 pg/mL	Normal to high
Sex hormone binding globulin (SHBG)	40–120 nmol/L	Low to normal
Total testosterone	2–45 ng/dL	Normal to high
Free testosterone (T)	0.1–6.4 pg/mL	Normal to high
Free androgen index (FAI)	7–10	Normal to high
DHEAS	Age 20–29: 65–380 ug/dL Age 30–39: 45–270 ug/dL	Normal to high
Androstenedione	28–230 ng/dL	Normal to high
Anti-Mullerian Hormone (AMH) <sup>2</sup>	>4.2ng/mL (automated assay) >5.6 ng/mL (manual assay)	High

\* We have listed standard ranges. You should ask for the reference ranges from the laboratory that performed your testing in order to compare your results.

There are also physical symptoms of hyperandrogenism that should be evaluated by your physician (next page).

The different criteria a woman meets will affect the ease of the diagnosis. If there is hyperandrogenism (H) along with oligo/amenorrhea (O) and/or polycystic ovaries (P), a diagnosis of PCOS can be made (assuming other similarly presenting conditions are excluded). It becomes a bit blurrier from our perspective when a patient presents with O + P only, as these are

the same symptoms that a woman with HA may exhibit<sup>10</sup>. In this case, the diagnostic criteria specifically state that HA must be excluded before making a diagnosis of PCOS<sup>11</sup>.

### Physical symptoms in PCOS

Symptom	Normal	PCOS	Frequency in PCOS
Hirsutism (FG Score)*	Score < 6	Score ≥ 6	21–76% Health at Every Size <sup>12</sup>
Acne	Perhaps some facial acne	Facial and chest/upper back, not responsive to standard treatments	50-58% <sup>13</sup>
Androgenic alopecia (scalp hair loss)	Not present	Sometimes present	16% <sup>14</sup>
Acanthosis nigricans (skin darkening / texture changes)	Not present	Sometimes present	23% <sup>15</sup>

\*Hirsutism can be quantitated through a “[Ferriman-Gallwey \(FG\) score](#),” in which the amount of hair on nine different areas of the body is graded on a scale of 0 to 5, and then the sum is taken<sup>16</sup>. The cutoffs for a “normal” score range from 5 to 8, depending on the investigator.

### When PCOS Is Actually HA

As we just mentioned, the category of PCOS that consists of amenorrhea and polycystic ovaries (O + P) shares the same symptoms as HA. In fact, somewhere between 15% and 55% of women with HA have multi-follicular or polycystic ovaries<sup>17</sup>, and obviously, missing periods. Doctors may diagnosis PCOS based on an ultrasound, along with amenorrhea, without understanding the precise requirements needed to qualify as polycystic ovaries ([outlined earlier](#)). In one recent study, if the PCOS diagnostic criteria were applied and HA not considered, 86% of women with HA would have been diagnosed with PCOS<sup>18</sup>. This makes it important for women to confirm a diagnosis of PCOS via methods other than ultrasound. The best way to do this is by looking at blood work and physical symptoms.

The next table compares blood work results if one has PCOS with what is expected in a woman with HA. There are a couple of key differences between the two conditions hormonally. First, LH is almost always lower than normal in women with HA, although occasionally it is normal. In women with PCOS, LH will at least be normal and is often elevated to two to three times FSH<sup>19</sup>. Second, E<sub>2</sub> is also often low in HA, but normal to high with PCOS. Finally, androgen levels will be normal with HA but are

often elevated in a woman with PCOS, especially free testosterone (T)<sup>20</sup>. If your blood work picture is HA-like and doesn't include any elevated androgens, it becomes much less likely that you have PCOS. Also, be aware that Anti-Mullerian Hormone (AMH) is being tested more frequently, with a high level thought to be associated with PCOS. However, women with HA often have similarly high levels so this can not be used to distinguish the two conditions<sup>21</sup>. Interestingly, HA can also be associated with quite low AMH values; see the HAers with low AMH table in [Chapter 20, "When You Need a Jumpstart."](#)

### Hormonal levels in HA and PCOS

Hormone	Normal result*	Expected value in HA	Expected value in PCOS
FSH	3.0–20.0 IU/L	Low to normal (around 6 IU/mL)	Low-normal to normal
LH	2.0–15.0 IU/L	Low to normal, less than FSH	Normal to high-normal, greater than FSH
E <sub>2</sub>	20–150 pg/mL	Low to normal	Normal to high
Total T	2–45 ng/dL	Low to normal	Normal to high
Free T	0.1–6.4 pg/mL	Low to normal	Normal to high
Free Androgen Index (FAI)	7–10	Low to normal	Normal to high
DHEAS	Age 20–29: 65–380 ug/dL Age 30–39: 45–270 ug/dL	Low to normal	Normal to high
androstenedione	28–230 ng/dL	Low to normal	Normal to high

\* We have listed standard ranges. You should ask for the reference ranges from the laboratory that performed your testing in order to compare your results.

The next table compares the physical symptoms. Keep in mind that “hirsutism” does not mean a couple of extra stray hairs here or there (we all have those). The hirsutism associated with PCOS is a much greater degree of [excess hairiness](#). And “acne” does not mean a few pimples on your face; with PCOS, severe acne on both the face and other body parts, and often resistant to prescription treatments, is common. The presence of these

symptoms may well suggest PCOS, but without them, again, HA is more likely the correct diagnosis.

Finally, lifestyle habits play a big part in correctly diagnosing HA over PCOS. If a number of the criteria below describe you and your habits, HA is much more likely than PCOS.

- being in a smaller than average body (although as we have discussed, HA does occur in women who are not “underweight”)
- recent significant weight loss (>10 lb)
- a history of a larger weight loss (>10% of bodyweight)
- recent increase in exercise time or intensity, such as adding a few Zumba classes, or training for a race
- frequent high intensity exercise, e.g., more than one hour/day, multiple days of the week
- running
- low caloric intake on a regular basis (<14 kcal/lb/day)<sup>22</sup>
- a diet restricting certain food groups (e.g., low carb or low fat)

### Physical symptoms in HA and PCOS

Symptom	HA	PCOS
Hirsutism (FG Score)	Score is 0–5	Score $\geq$ 6
Acne	Some facial; sometimes increased with weight gain	Facial and chest/upper back; often resistant to treatment
Androgenic alopecia (scalp hair loss)	Not present, although hair can be brittle	Sometimes present
Acanthosis nigricans (skin darkening/ texture changes)	Not present	Sometimes present

Among our survey respondents, 15% were diagnosed with PCOS by a doctor, and another 20% were told PCOS was a possibility. Unfortunately, we do not have sufficient data to make an assessment of whether these diagnoses met the criteria we are suggesting here. However, we can tell you that of those who reported blood work results, androgens were only tested in 45%, and elevated in less than half of those. This implies that in many instances the diagnosis of PCOS was based solely on lack of periods and the appearance of the ovaries on ultrasound examination, therefore HA was much more likely the correct call.

Among our survey respondents, the women diagnosed with PCOS regained cycles at a similar frequency after following the Recovery Plan, with very similar weight gains compared with those not diagnosed with PCOS. This supports the argument that their amenorrhea was likely caused by HA.

*Nadia: I was diagnosed with PCOS. It was something I fought for over five years before I found a doctor who knew what HA was. She told me I likely never had PCOS and that it was possible that thinking I did (and changing the way I ate and exercised because I thought I did) made my HA worse. With my diet I had gone low carb: very limited starches, limited fruit, limited sugar, no gluten, and lower fat. I exercised daily for no less than 30 min, and often close to an hour. It was a lot of cardio (walking), but also weight training. (Nadia's PCOS was subsequently confirmed by two different endocrinologists, but she was still able to conquer HA and regain her cycles by three months of consistent, "all in" work toward recovery.)*

While it is true that many women who are told they have “lean” PCOS probably have HA instead, it is also possible for an individual to have both PCOS and HA. The PCOS hormonal imbalances are not hypothalamus-derived, so they can be present at the same time the hypothalamus is shutting down the reproductive system because of underfueling, stress, or overexercising. In general it seems HA trumps PCOS; that is, if both are present, the hormonal and physical picture will be more HA-like. Once an individual is recovering or recovered from HA, more PCOS-like symptoms may become apparent<sup>23</sup>, both biochemical (e.g., blood work) and physical. Although in many cases the appearance of PCOS-like symptoms after HA recovery is only temporary<sup>24</sup>.

To reiterate, if all your blood work is normal, and your doctor just noted there were “a lot” of follicles in your ovaries (possibly without counting them), PCOS may not be the correct diagnosis.

## Does It Matter If I Have PCOS or HA?

As far as getting pregnant goes, there aren't huge differences in recommended methods for HA versus PCOS; one can usually try naturally (perhaps with additional supplements that will be discussed in the “[I definitely have PCOS](#)” section) if cycles are restored, or use oral medications, injectables, or IVF. The biggest concern with multifollicular or polycystic ovaries is that the more follicles one has, the greater likelihood there is for ovarian hyperstimulation syndrome (OHSS) if injectables or IVF are used. OHSS

is a complication of fertility treatments in which your ovaries become very swollen, and in severe cases leads to fluid buildup in your abdomen and chest, sometimes requiring hospitalization. Doctors should be mindful of the possibility of OHSS when choosing dosages for these treatments in women with high numbers of follicles. For more discussion on the possible ovulation induction methods and avoiding OHSS, read [chapters 20 through 23](#). Much of what we discuss in those chapters is applicable to both HA and PCOS.

Where the diagnosis matters most is in recommendations for lifestyle modifications. Typically, women with PCOS are told to exercise more and eat less, which has been found in some cases to reduce the hormonal effects of PCOS<sup>25</sup> (although long-term compliance is a serious issue with these recommendations). However, this is the exact opposite of what one needs to do to recover from HA, so receiving the correct diagnosis is important.

*Jessica O:* After a year of unsuccessfully trying to conceive (TTC), my doctor ran a bunch of tests and did an ultrasound. Everything was normal, except that the ultrasound showed ovarian cysts. So, they diagnosed me with PCOS and put me on metformin. I actually ended up getting pregnant the very next month. I don't know if the metformin helped, or if it was just the fact that it was over the holidays, so I was eating more and exercising less than usual. At any rate, I lost the pregnancy fairly early on. After that, I decided to get serious about treating my supposed PCOS, so I went on a low carb diet, lost some weight, and became obsessed with getting my daily workouts in. Surprise, surprise; at that point, I developed full-blown HA. My doctors continued to assume that my problems were caused by PCOS and no one knew why things were getting worse rather than better. It was an incredibly frustrating experience. I was never actually diagnosed with HA, but when I found Nico's blog and the Board, it all started to make sense. I gained weight, cut back on exercise, and regained my cycle.

*Katherine:* Don't get sucked into the "maybe I have PCOS and can exercise as much as I want" trap. Been there, doesn't work.

## HA and PCOS??

There are women who have both HA and PCOS, as we described earlier<sup>26</sup>. When HA is active, they exhibit the classical symptoms of HA—low LH and E<sub>2</sub>, often along with the physical issues like being cold all the time, low libido, night sweats, brittle hair and nails, etc. Once they recover from HA

by eating more and exercising less, their hormonal profile swings to be more PCOS-like, with perhaps an LH level that is higher than FSH, and a higher E<sub>2</sub>, along with increased androgens and possibly physical manifestations of PCOS<sup>27</sup>. The latent PCOS may prevent cycles from returning to normal even after recovery from the HA component. Amenorrhea may persist, or cycles can continue to be lengthy and/or irregular. So, treatment may still be needed to induce ovulation for pregnancy, despite HA recovery. It is worth noting that in some women LH increases to more than FSH with no other symptoms of PCOS. In these cases we suggest waiting a few months and retesting, as the increased LH may simply be a consequence of the hypothalamus overshooting and speeding up too much<sup>28</sup>.

*Grace:* I was diagnosed with both PCOS and HA. My doctor did extensive testing to confirm that I had both. I did all of the ultrasounds and hormone testing, but he also had me completely cut out exercise for a while and then add it back in to see how my hormone profiles adjusted. When I cut out exercise, the labs showed more of a PCOS profile, but when I added it back, all levels were low, an HA profile. I also have the cystic ovaries and abnormal hair growth.

If it turns out that you do have PCOS in addition to HA, it can be a discouraging realization, especially if you have already worked to recover from HA. You may question everything you've done—did you make things worse by gaining weight and not exercising as much? You might feel like the only thing you've accomplished is to go from one problem to another.

That is not the case! If you have PCOS masked by HA, and want to get pregnant, you have two issues to overcome—first the HA, then the PCOS. Once you recover from HA, the first and overriding issue, your likelihood of ovulating on your own is higher. If you aren't able to ovulate on your own and need help from treatment, your chances of responding are significantly better when you are not trying to work around both an energy deficit and the issues caused by PCOS.

*Liz:* I cycled regularly for two years (age 13–15). Then my periods started to become slightly irregular and I got some PCOS symptoms without any dietary changes. Then I started restricting, and boom, my period was nowhere to be seen. I definitely have PCOS-like symptoms now, but I started cycling for the first time in forever when I started eating a normal amount of calories for the amount of energy I expend (and being more intuitive and not restricting). I also take some herbs and vitamins, but I did this throughout the years, and until I completely stopped restricting

and gained weight I did not have a period. My thinking I had PCOS absolutely contributed to my restriction. Even after I got my eating disorder under control, I was obsessed with maintaining a certain weight and never letting myself gain, even if it meant eating very little, thinking I was controlling my PCOS when actually I was preventing myself from cycling. *(After many years of visits to endocrinologists, a 17-OH-progesterone test showed that Liz has late-onset congenital adrenal hyperplasia, a condition that manifests similarly to PCOS.)*

*Shayla:* I was diagnosed with HA in July 2011 and didn't commit to making true, significant changes until the end of the year. Between July and December, I would throw in an intense spin class or exercise a couple days harder than I should have. December is when I got real with myself and realized that I needed to commit to a lessened exercise routine in order to see results (four to five days per week, 40 minutes max, walking or easy elliptical). From July 2011 to January 2012, I got my weight up to a BMI of 22. And while I haven't gotten a natural period because I have hormonal PCOS, I know I recovered from HA since I tried Provera a couple weeks ago and got a significant, heavy bleed from it—marked improvement since I had failed it in July 2011. So all in all, with significant changes made around December and my weight at a BMI of 22 in January, now I'm responding to treatment. I'd say it took me about three to four months. And to be honest, what every single woman has said here is absolutely true. For a while last year, I was in denial about it all, but if you really commit to gaining, eating healthy fats, and lowering your exercise, you WILL respond to treatment or get your period naturally. *(Shayla got pregnant with her son on her second round of Femara. Her second child, a daughter, was naturally conceived)*

## I Definitely Have PCOS

If you have PCOS and not HA masquerading as PCOS, the obvious next question is, now what? There are two areas of concern: 1) management of the syndrome (perhaps with future pregnancy in mind), and 2) longer-term health issues associated with PCOS. We are far from experts on PCOS, but recent research we discuss below suggests some avenues for you to consider and explore.

Lifestyle modifications, medications, and nutritional supplements can potentially help manage PCOS by:

- lowering androgen levels

- improving insulin resistance
- promoting ovulation (if cycles were absent or irregular), which can lead to pregnancy
- perhaps improving ovarian morphology

Discussing all the possible alternatives to help with these symptoms is beyond the scope of this book. We will cover a few options here; we recommend finding a “[Health at Every Size](#)” dietitian to help manage symptoms without focusing on losing weight, along with having a conversation with your doctor about what (if any) treatment plan is most appropriate for you. You may want to visit the website “SoulCysters: Women with PCOS Speak from the Heart” ([www.soulcysters.com](http://www.soulcysters.com)) to learn more.

First, lifestyle modifications. Weight loss and exercise use to be commonly recommended to manage complications such as insulin resistance that seem to possibly respond to such interventions (although long term benefits are unclear<sup>29</sup>), however, as stated, some dietitians are working with patients to manage symptoms without focusing on weight. It does seem that exercise in moderation can be beneficial. If you have an HA/PCOS combo, keep in mind that reduced exercise is needed in the short term for recovery from HA ([chapter 12, “The HA Recovery Plan: Exercise Changes”](#)); it can be added (slowly!) in the longer term as your HA recovery stabilizes. After you work on recovery and achieve a natural cycle, we encourage you to continue with your new, improved lifestyle for at least three months before you consider making any changes, like changing eating patterns or increasing exercise. That way, you allow your body to trust that you are not going to return to an energy deficit. Women who have immediately added exercise or cut calories once regaining their cycles have been much less regular than those who waited for at least the recommended three months. Once you’ve got a few natural cycles under your belt and you decide to make changes, incorporate them slowly and pay attention to your cycles to note any effects ([chapter 16, “Recovering Natural Cycles”](#)).

A different lifestyle approach that has showed improvements in PCOS symptoms involves changing the timing of meals. Women with PCOS were put on a meal plan in which they consumed 54% of their calories at breakfast, between 6:00 and 9:00 a.m., 35% at lunch (noon to 3:00 p.m.), and only 11% at dinner (6:00 to 9:00 p.m.)<sup>30</sup>. Their diets were also high in protein, at 0.64g/lb, which reportedly helped them to feel full and satisfied throughout the day. After three months, hormones were normalized (androgens and insulin decreased, sex hormone-binding globulin increased)

to the same extent as when the medication metformin (a standard PCOS treatment) was used (see [table on p. 14](#)). In addition, more frequent ovulations were observed, commencing between one and three months after dietary changes were implemented. The more frequent ovulations are clearly helpful when one is trying to conceive. There are no long-term follow-up studies, but there are few concerns with side effects from a dietary change like this.

It may feel overwhelming to consider making breakfast your biggest meal of the day, especially if you had/have to modify your eating patterns significantly in order to recover from HA. So if this is something that interests you, perhaps you could start by adding more protein to your breakfast and making that a higher calorie meal, without going as far as making it more than half of your calories for the day.

A second option for managing symptoms of PCOS is medication. Metformin is a standard treatment for PCOS that reduces the amount of glucose produced by the liver. As a side effect, it also improves some of the other hormonal and physical symptoms of PCOS (see [table](#)). However, metformin can cause gastrointestinal discomfort and weight loss, which is not recommended for those who have or had HA.

A third solution to ameliorate PCOS symptoms is nutritional supplementation, including d-chiro-inositol and/or myo-inositol<sup>31</sup>. These dietary supplements are readily available at health food stores. The [table on the next page](#) includes data on reductions in androgens and insulin sensitivity in individuals taking d-chiro-inositol.

Based on the results, d-chiro-inositol seems like an attractive option; however, these are early data, so consult with your doctor and look at the latest research. If you are trying to get pregnant, other studies suggest that myo-inositol may be a better option, as myo-inositol was found to be associated with more mature eggs and a higher pregnancy rate than d-chiro-inositol in an IVF study<sup>32</sup>—unfortunately hormonal data were not provided.

For discussion of other methods of achieving pregnancy, see [part 3, “When it Takes More Than an Oops to Get Pregnant.”](#)

## Effects of PCOS treatment options on hormones and ovulation.

Treatment	50% of calories at breakfast <sup>33</sup>	Metformin <sup>34</sup>	D-chiro-inositol <sup>35</sup>
Study Duration	3 months*	6 months*	6–8 weeks*
Free Testosterone	–50%	–67%	–73%
DHEAS	–35%	–23%	–49%
Androstenedione	–34%	NR	–27%
SHBG†	116%	–13%	138%
Fasting insulin	–53%	–61%	–36%
% ovulating in test group (% in control group)			
First month	0% (0%)	0% (0%)	60% (0%)
Second month	28% (7.6%)	10% (0%)	NA (20%)
Third month	50% (20%)	50% (5%)	NA
Months 4-6	NA	95%	NA

\* Note: Negative numbers indicate decreases in listed hormones

† Sex hormone-binding globulin, used in calculation of free androgen index (FAI); an increase yields a lower, improved FAI. (FAI = 100 \* Total T / SHBG)

NR = Not reported

NA = Not applicable (e.g., study too short)

## Long-term Concerns With PCOS

When you are diagnosed with PCOS, you probably also hear about the potential long-term complications: diabetes, heart disease, and cancer. By now you may feel weary—yet more health issues to worry about, on top of the issues from HA. Research suggests that women in smaller bodies are less likely to manifest the complications of PCOS, including insulin resistance and poor cardiovascular health markers<sup>36</sup>. Therefore, the PCOS health risks that we discuss further in this section are unlikely to be problematic for a typical woman who has experienced HA. You should discuss the risks with your doctor at your annual physical—but other than that, leave them at the bottom of your worry list. We really want to stress this. We are only mentioning these long-term complications because we don't want you to be concerned if you read about PCOS and see references to the potential health risks. In someone who has experienced HA, the chances of these complications are low—probably no higher than a regular woman without PCOS<sup>37</sup>.

Still worried? Let's take these long-term issues one by one. First, the criteria for a diagnosis of metabolic syndrome (MetS), which is thought to be the precursor to diabetes and heart disease, are three out of five of the following<sup>38</sup>:

- high waist circumference (> 35 inches)
- triglycerides > 150 mg/dL
- high-density lipoprotein-C (HDL-C) < 50 mg/dL
- blood pressure > 130/85
- a fasting and 2-hour glucose reading from a glucose tolerance test > 110mg/dL and > 140mg / dL respectively

Although studies have suggested a link between PCOS and cardiovascular disease based on blood work (e.g., high cholesterol), the clinical research to date does not support a strong association<sup>39</sup>. The cardiovascular risk is based on insulin resistance being associated with greater susceptibility to the disease, as well as abnormal processing of cholesterol and other lipids. Additionally, the two factors most correlated with risk of cardiovascular disease are an abdominal waist measurement greater than 35 inches and an above normal non-HDL cholesterol. Your doctor should gauge your risks by assessing your psychosocial stress, blood pressure, glucose, lipid profile (cholesterol, triglycerides, HDL, LDL, and non-HDL cholesterol), waist circumference, physical activity, nutrition, and smoking<sup>40</sup>. If the results suggest an increased risk, you can work together to develop a plan for the future.

The final potential long-term consequence of PCOS that has been suggested is endometrial cancer (cancer in the lining of the uterus). Many studies have been performed through the years with conflicting results; a recent analysis of multiple studies found a possibly three-fold increased risk in women with PCOS<sup>41</sup> (9% versus 2-3% in the overall population). However, the criteria used for PCOS diagnosis were not high quality in all studies. Theories attribute the increased risk to<sup>42</sup>:

- uterine lining buildup because of high estrogen, with irregular shedding due to oligomenorrhea or amenorrhea
- increased levels of LH (and receptors for LH in the cancerous cells)
- increased levels of insulin (and receptors for insulin in uterine lining), increased levels of leptin, and decreased levels of adiponectin, all associated with fat mass
- increased estrogen due to high insulin levels

If you do *not* have increased LH, estrogen, or insulin<sup>43</sup>, your risk of endometrial cancer is unlikely to be higher. Most hormonally-driven endometrial carcinomas seem to derive from long-term higher estrogen exposure without progesterone in opposition. With the estrogen level of <20 to 30 typically seen with HA the uterine lining remains thin and therefore not of concern. If your estrogen levels are higher and your uterine lining does build up without a regular bleed, you could talk to your doctor about using progesterone pills or cream to shed the lining from time to time<sup>44</sup>. Regardless, PCOS-related endometrial cancer is slow to develop and often found at an early stage due to abnormal (mid-cycle or post-menopausal) bleeding in middle-aged or older women, so if you and your doctor are aware of your potential risk and maintain vigilance, you should be able to catch it early and treat it.

Again, these side effects do not occur in everyone with PCOS, and if they do manifest, the symptoms are usually mild in women who formerly had HA.

## In Summary: PCOS or HA?

We know many women who were given a diagnosis of PCOS because they were not getting their periods and had “polycystic-looking ovaries.” With no other symptoms or corroborating blood work, and especially with other HA risk factors in play, PCOS is almost certainly not the correct diagnosis. Instead, it is much more likely you have HA. Many healthcare professionals seem to be unaware that research shows a high proportion of women with HA exhibiting polycystic-like ovaries. It is also possible to have both HA and PCOS. In this case, one needs to work to overcome HA first and then potentially (and slowly) make dietary and exercise changes to help manage PCOS symptoms. Do not let a possible PCOS diagnosis lure you into thinking that restrictive eating and excessive exercise habits are a wise choice. If what we have described in earlier chapters rings true for you, please give the HA Recovery Plan in [part 2 \(“The Recovery Plan—Changing Your Habits and Your Life”\)](#) a try and see what happens.

*Lisa:* I know... the possibility of PCOS on top of having HA adds to the confusion and concern, and certainly doesn't make your decisions any easier. These frustrations among HA/PCOS gals have been echoed repeatedly, so know you are not alone. With that being said, what we *don't* want to see happen is for you to start waving the “I have PCOS, not HA” flag, derailing you off the track for HA recovery. (Can you tell we have

heard that?) I only caution you because I can assure you that if I had a possible diagnosis of PCOS, you can bet your bottom dollar that I would not have decreased exercise and gained weight in order to recover. Heck no! And on top of that, I am certain doctors would have recommended not gaining weight because of my “average” BMI. Only you know deep down if there is a possibility that restrictive eating and/or exercise are contributing factors to your HA, muddying the waters of a PCOS diagnosis. There is only one way to find out and, again, it’s temporary and totally within your control.

So at this point you have possibly begun to consider that you might have both PCOS and HA and have chosen to press on with the HA solution; or you are concerned that you might have only PCOS and not HA and sure don’t want to risk lifestyle changes for “what ifs.” No one can tell you which path to take, but what we can do is give you a few things to think about.

- 1) If you press on with HA recovery and do indeed have both HA and PCOS, you will then only be dealing with PCOS, as opposed to both, and get all the benefits from option 2 below.
- 2) If you press on with HA recovery and do not have PCOS but only HA, then YAY! You will recover, your bones will likely increase in density, your brain and heart will be in tiptop shape, you will cycle regularly, and if you decide to make babies you will now have that option.
- 3) If you press on with HA recovery and don’t actually have HA but do have PCOS then you should play the lottery because I doubt that will happen. Yet let’s just say it’s a possibility. Your choice.

## For More Information...

[Work with Dr. Nicola Rinaldi \(www.noperiodnowwhat.com/consulting\)](http://www.noperiodnowwhat.com/consulting)

We would like to thank [Kate Albarella RD, LDN](#) for reviewing and providing feedback on this chapter. She is a dietitian who works with women with PCOS; if you find that you DO have PCOS, please consider working with her. [TheDietitianKate@gmail.com](mailto:TheDietitianKate@gmail.com)

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