

## What is Klinefelter syndrome? How do I support a partner who has it? <sup>[1]</sup>

(1) Dear Alice,

A man I met said he has two X chromosomes and one Y chromosome ? is there a name for this that I can look up information on?

(2) Dear Alice,

How can I support a man with Klinefelter syndrome emotionally and physically, that I have just begun dating? He was very blunt and upfront with his condition.

Sincerely,

Caring Partner

### **Answer**

Dear Reader and Caring Partner,

Having two X chromosomes and one Y chromosome (or a genotype of XXY, instead of XY) does indeed have a name ? and that name is Klinefelter syndrome! Bravo for wanting to find out more about this condition that occurs more often you might suspect. Klinefelter Syndrome ? or KS for short ? affects one out of every 500 to 1,000 baby boys of all races and ethnicities, although many people might not be diagnosed until adulthood. Why you ask? Because the symptoms aren?t always totally easy to spot and can vary depending on a man?s age. Because KS involves a random error in sex chromosomes (a.k.a. the chromosome that differentiates a fetus into a male or a female), men with KS often have smaller testicles and therefore don?t produce as much testosterone. Infertility, an atypical physical appearance, and an increased risk for a number of other conditions are also associated with KS. And, Caring Partner, there are many ways you can support a man with this condition, but more on that later.

Although these related issues may sound severe ? and they can indeed significantly impact some men?s lives ? many men don?t even know they have KS until puberty or later, because their symptoms never interfered enough with their wellbeing for them to seek help. In fact, the average age of diagnosis for men with KS is around 30, even though it?s a condition that?s present from birth. And, even then, many only find out about their KS because they undergo

tests for fertility issues. However, boys and men with KS may definitely have symptoms that are noticeable or bothersome, including:

- Above-average height
- Increased abdominal fat
- Low muscle mass or difficulty building muscle
- Little body hair
- Gynecomastia (or enlarged breast tissue)
- Sexual dysfunction or infertility (i.e., little or no sperm production)
- Weak bones and frequent bone fractures

While this list might give a bit of insight into the day-to-day impacts of KS, there are a number of complications associated with it as well. Younger boys with KS may experience delayed puberty and speech or learning difficulties, especially with language development. In the bigger picture, men with KS may live slightly shorter lives than average men. This may be, in part, because they are at increased risk for diabetes resulting from the combo of increased abdominal fat plus less physical activity (due to concerns about physical appearance, limitations of low muscle mass, or fear of bone fractures). Another possible reason for lowered life expectancy is the increased risk of male breast cancer in men with KS.

Fortunately, testosterone replacement therapy can improve many symptoms, especially if the man begins taking it before or during puberty. This can be an injection, gel, patch, or oral strip, and it often ends up being taken for the course of his life. The great thing about this treatment is that, not only will it help the man feel or appear more masculine (more muscle mass or body hair), but those with KS also report higher energy levels and better moods. Though some studies do show that testosterone therapy may improve learning and speech disabilities for those with KS other studies have not. More research is needed to further investigate the impact of testosterone on these disabilities. Other lines of treatment include speech therapy, educational support, breast tissue removal, or fertility treatments (such as exciting new technologies that can extract the small amount of sperm some men with KS produce to fertilize an egg). Men with KS also often find that support groups can be helpful. You might consider sharing resources about support groups with these men you both know, such as an organization called [AXYS](#) [2].

Caring Partner, you ask how to best support the man you're dating. **Emotionally supporting** him can take a variety of forms, such as just being there for him if he's down, validating his choices in managing his KS, and accepting his differences. Simply offering a listening ear as he makes treatment decisions can also make a positive impact. Over time you'll likely build up trust, and it may become easier to talk about sensitive issues. **Physically supporting** your partner is also something that's good to be open and honest about from the beginning. Intimacy may take time, so it might help to communicate proactively about each other's physical needs, desires, and limitations. He may have been so upfront and blunt because he feels self-conscious about the physical effects of KS, so you might consider a slow approach to being intimate. As always, communicate, communicate, and communicate some more!

Both of you may find that a great way to learn about KS is to simply ask these men you know about it, as long as you're willing to respect their right to decline to answer. Being willing to learn and to explore resources are great ways to inform yourself about this condition, support these men, and learn about the complexities and mysteries of genetics and life!

Alice!

Category:

[General Health](#) [3]

[Miscellaneous](#) [4]

[Relationships](#) [5]

[Relationship Stuff](#) [6]

[Sexual & Reproductive Health](#) [7]

[Men's Sexual Health](#) [8]

[Reproduction](#) [9]

[Fertility](#) [10]

## Related questions

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[How do I tell my girlfriend I'm sterile?](#) [12]

[My hairless face is holding me back ? I look too young!](#) [13]

[Tired of waiting for puberty](#) [14]

## Resources

[Disability Services](#) [15]

[Medical Services \(Morningside\)](#) [16]

[Medical Services \(CUMC\)](#) [17]

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## Footer menu

- ▼ [Contact Alice!](#)
  - [Content Use](#)
  - [Media Inquiries](#)
  - [Comments & Corrections](#)
- ▼ [Syndication & Licensing](#)
  - [Licensing Q&As](#)
  - [Get Alice! on Your Website](#)
  - [Full Site Syndication](#)
  - [Link to Go Ask Alice!](#)

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### **Links**

- [1] <http://goaskalice.columbia.edu/answered-questions/what-klinefelter-syndrome-how-do-i-support-partner-who-has-it>
- [2] <http://www.genetic.org/>
- [3] <http://goaskalice.columbia.edu/category/general-health>
- [4] <http://goaskalice.columbia.edu/category/miscellaneous-1>
- [5] <http://goaskalice.columbia.edu/category/relationships>
- [6] <http://goaskalice.columbia.edu/category/relationship-stuff>
- [7] <http://goaskalice.columbia.edu/category/sexual-reproductive-health>
- [8] <http://goaskalice.columbia.edu/category/mens-sexual-health>
- [9] <http://goaskalice.columbia.edu/category/reproduction>
- [10] <http://goaskalice.columbia.edu/category/fertility>
- [11] <http://goaskalice.columbia.edu/answered-questions/hypogonadism>
- [12] <http://goaskalice.columbia.edu/answered-questions/how-do-i-tell-my-girlfriend-im-sterile-0>
- [13] <http://goaskalice.columbia.edu/answered-questions/my-hairless-face-holding-me-back-%E2%80%94-i-look-too-young-0>
- [14] <http://goaskalice.columbia.edu/answered-questions/tired-waiting-puberty>
- [15] <http://goaskalice.columbia.edu/resource/disability-services>
- [16] <http://goaskalice.columbia.edu/resource/medical-services-morningside>
- [17] <http://goaskalice.columbia.edu/resource/medical-services-cumc>