

Talking to Others about Being At-Risk

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Why Don't People Talk about HD?

- Find it stressful
- Was not discussed growing up
- Family guilt
- Person with HD denies illness
- Family doesn't know you know

Why Should
People Talk
about HD?

SUPPORT!!



Who?

- Family
- Friends
- Dating
- Co-Workers
- Employers
- Health Care Professionals

Choices

- There is no “right” or “wrong” way to disclose a HD status.
- Each person needs to make their own decision.

Important!

- First, think about consequences
- Think about relationships (directly and indirectly) and how discussing HD can impact these
- Think about your goal
- If you are an adult who is at-risk, you should (at-least) look into benefits and coverage

Types of Benefits and Coverage

- Health Insurance (Group plans cannot ask for personal info)
- Dental Insurance
- Life Insurance (Might include a rider to use funds prior to death)
- Disability Insurance (Long and short term)
- Long Term Care Insurance (Pot of money to use for self-care)

A large red speech bubble graphic with a white border, containing the word "Remember!" in white text. The bubble has a tail pointing towards the bottom left.

Remember!

- Once you discuss information or post it ANYWHERE on the Internet, you have no control of where that information might go or who will have access to it.

Family

- Many times family members feel the best way to protect each other is to avoid discussions.
- Usually causes more issues and stress in the long run.
- You can decrease the stress by having a discussion before gene testing. “I’m thinking about going for testing”:
 - Would you want to know?
 - Would you want to go with me?
 - Would you want to find out the results?

A large red speech bubble graphic with a white outline, pointing downwards. The word "Family" is written in white serif font inside the bubble.

Family

- If you tell someone in your family:
 - Will they tell others ?
 - Will someone else find out “accidentally”?
 - Will you be burdening them by asking them not to tell?

Family: Cons and Pros

- Cons:
 - Keeping a secret can be stressful and can “take a toll”
 - Need to keep track of what you said to whom
 - Need to keep track of what others might say
- Pros:
 - Talking to family is usually less stressful than anticipated
 - Talking to family in advance gives control
 - Families can be a great support



Family

- Know that some family members might not want to have this discussion. Be respectful of this.
- Remember, just because your family did or did not discuss HD in the past does not mean you need to do the same.
- Make sure you talk through your feelings with a counselor. Then you can move forward with your plan.

Friends

- There are many ways to talk to friends about your HD status:
 - “Hi my name is ... I’m at-risk for HD”
 - Wear HD related items
 - Form trust, then talk about HD
 - Never talk about it

Friends: Cons and Pros

- Cons:

- Keeping this news secret can be stressful
- Need to keep track of what you said to whom
- Need to keep track of what others might say (intentionally or unintentionally)
- If sharing, fear of losing friends

- Pros:

- Friends can be a great support (find out who is really there for you)

Dating

- There are many ways to talk to a new significant other about your HD status:
 - “Hi my name is ... I’m at-risk for HD”
 - Wear HD related items
 - Form a relationship, then talk about HD
 - Never talk about it

Dating: Cons and Pros

- Cons:

- Keeping this news secret can be stressful
- Fear that you are lying to them
- If sharing, fear they will not stay in the relationship
- If sharing, fear that you are “damaged goods”

- Pros:

- Find out who will be willing to stay in the relationship
- Significant other can be a great support

Co-Workers

- Many ways to speak to co-workers
- Need to determine the goal
- Consider the consequences
- If you decide to talk about HD, minimize potential damage:
 - When
 - How
 - Who

Co-Workers: Cons and Pros

- Cons:
 - Keeping this news secret can be stressful
 - If sharing, will co-workers “judge” you or question decisions
 - If sharing, will co-workers use this against you
- Pros:
 - Co-workers can be supportive
 - Requesting time-off might be easier

Employers

- Many ways to speak to employers
- Need to determine the goal
- Consider the consequences
- Talk to supervisor and HR
- Be aware that if using health insurance through employer, employer will have access to info

Employers: Cons and Pros

- Cons:
 - Employers might indirectly use info against person at-risk
- Pros:
 - Might receive support from employer

Health Care Professionals

- Be cautious about disclosing information prior to obtaining benefits
- Any individual benefit (compared to a group policy) can and will require medical records
- “Doctor Hopping”, once you have medical information, can be illegal if you sign a medical insurance policy with a false claim
- Take care of benefits FIRST

Health Care Professionals: Cons and Pros

- Cons:
 - Not disclosing may cause symptoms to go unnoticed
 - Once disclosed this information will become part of the medical record
- Pros:
 - Talking to health care professionals can help to create baseline for the future
 - Health care professionals can refer to specialists

Final Words

- No wrong or right way to talk to others
- Keeping secrets can be stressful
- Important not to decide for others
- Others can be supportive
- Talk to people who have “gone through it”
- Important to take care of your self