

## Quick Guide for Health Care Professionals: Helping Your Patients Make Disclosure Decisions

When a patient hears the words “you have cancer,” there are so many decisions that have to be made, including deciding to whom and when they are going to tell about their diagnosis. This guide may help as you navigate your patients through their choices around disclosure.

### 1. Are your patients planning on sharing their diagnosis with their **family members**?

- Family members are often the first people patients disclose to, starting with their spouse or significant other, and then moving onto children. Children are resilient and can handle this kind of information, but it is important to have the answers to their questions ready.
  - Younger children may ask questions like what is cancer? Is cancer contagious? Why did you get cancer? Will you die? Patients should be prepared for these tough questions and even consider practicing the answers.
  - There are several books written specifically for children, to help them process and cope with this information. For example: [When Someone You Love Has Cancer: A Guide to Help Kids Cope](#) by Alaric Lewis. The National Comprehensive Cancer Network has useful resources at [https://www.nccn.org/patients/resources/life\\_with\\_cancer/talk\\_to\\_children.aspx](https://www.nccn.org/patients/resources/life_with_cancer/talk_to_children.aspx)
  - With older and adult children, a patient can state three pieces of necessary information (e.g., the type of cancer, the treatment, and anticipated outcome), then ask if they have any questions.
- You can help your patients prepare a script, especially if certain phrasing is important to the patient or if the information they are explaining is complicated.



### 2. Are your patients planning on sharing their diagnosis with their **friends**?

- Support: Disclosing to friends may also be an important step for your patient to receive emotional and physical support throughout treatment and recovery.
  - One way to minimize the strain of disclosing, is to tell close friends in person, and then enlist those friends to notify mutual friends. However, make sure everyone understands exactly what the patient want shared with others.
- Help: Friends will likely want to help, so patients should be prepared with specific ways they can help. Otherwise, they may find the “help” unhelpful. For example, do they need help walking their dog, picking up kids from school, a meal train, organizing mail or medical bills, start a [MyLifeline.org](http://MyLifeline.org) Helping Calendar, etc.
- Social Media: Social media has become a common avenue for sharing medical news, but there is a risk that personal medical information could be viewed by strangers, employers, etc. [CaringBridge.org](http://CaringBridge.org) is a free service that allows patients to set up a private news-sharing website that can be viewed only by approved friends and family, according to the patient’s wishes. Remind the patient to make choices about the privacy settings and that they should make their wishes around disclosure clear to anyone they invite onto their site.

3. Are your patients planning on sharing their diagnosis with their **employers**?

- ◆ Your patient is generally not required to disclose their medical information to their current employer or their future employers. It is a personal decision that each patient should make consciously, taking into account a variety of factors discussed here.
- ◆ However, there are times when the patient may need to share some medical information with their employer:
  - ◇ If they want to use the ADA or state law protections against disability discrimination, the employer must be provided some information about their medical condition.
  - ◇ If they are requesting a reasonable accommodation under the ADA or state law, they will need to explain why such an accommodation is needed.
  - ◇ If they are requesting FMLA leave, they will need to explain why the leave is necessary. In these circumstances, you can work with your patient to complete medical certification forms in accordance with their disclosure preferences. The Triage Cancer Quick Guide to Disclosure, Privacy and Medical Certification Forms is available at <http://trinecancer.org/QuickGuide-Disclosure>.

4. Are your patients planning on sharing their diagnosis with their **co-workers**?

- ◆ Disclosing to co-workers may be an important step to receive emotional and physical support at work.
- ◆ Co-workers can also be friends, so patients should be prepared for offers of help.
- ◆ Patients should be clear with any co-workers they disclose to about what they want shared with others, if at all.
- ◆ Patients should be prepared with three pieces of necessary information (for example, the type of cancer, the treatment and the anticipated outcome), then ask if they have any questions.
- ◆ Patients should try and make an honest assessment of who is trustworthy with their private information.
- ◆ If your patients have decided to keep their diagnosis private from their employers, you may want to advise them to make cautious decisions about what they share with co-workers.



Decisions around disclosure are deeply personal and situationally specific. These are general guidelines to help your patients start to think through to whom, when, and how they might disclose their diagnosis.

For more information about the Family and Medical Leave Act (FMLA), the Americans with Disabilities Act (ADA) and other cancer survivorship topics, visit <http://trinecancer.org/QuickGuides>.