





## **Making Disclosure Decisions**

Choosing to disclose your health diagnosis in the workplace is a personal decision and should only be made after thoughtful consideration of many factors. Some individuals feel very confident that sharing their diagnosis in the workplace and in other arenas is right for them. Others have concerns about sharing their diagnosis for a variety of reasons. There is no "one-size fits all" answer to disclosure. This Quick Guide is intended to help you make educated disclosure decisions and to help you avoid situations where you might unintentionally disclose your diagnosis.

## **Legal Protections**

You have privacy rights relating to your medical information, and these laws protect your rights in different ways:

## <u>ADA</u>

The Americans with Disabilities Act is a federal law that protects eligible employees with disabilities from discrimination in the workplace and provides access to reasonable accommodations. The ADA includes specific rules about how much information about your medical condition you have to share with an employer in order to be protected by the ADA or access reasonable accommodations. The ADA is enforced by the Equal Employment Opportunity Commission (eeoc.gov). For more information about the ADA and reasonable accommodations: TriageHealth.org/quick-guides/ada and TriageHealth.org/quick-guides/reasonable-accommodations.

## **FMLA**

The Family and Medical Leave Act is a federal law that allows eligible employees to take unpaid time off for certain medical reasons or to act as a caregiver. The FMLA includes specific rules about how much information about a medical condition you have to share with an employer when asking for FMLA leave. The FMLA is enforced by the U.S. Department of Labor (dol.gov/whd/fmla/index.htm). For more information about the FMLA, visit the Department of Labor Wage & Hour Division (dol.gov/whd/fmla), and the Quick Guide to FMLA (TriageHealth.org/quick-guides/fmla).

#### **HIPAA**

The Health Insurance Portability and Accountability Act is a federal law that requires your health care providers to get your permission before giving your personal health information to third parties. For more information, visit Your Rights Under HIPAA (<a href="https://hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html">https://hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html</a>) and Employers and Health Information in the Workplace (<a href="https://hhs.gov/hipaa/for-individuals/employers-health-information-workplace/index.html">https://hhs.gov/hipaa/for-individuals/employers-health-information-workplace/index.html</a>).

## **State Laws**

There are also state laws that may provide additional protections, access to reasonable accommodations, and medical leave. For more information about your state's laws, visit <a href="mailto:TriageCancer.org/StateLaws">TriageCancer.org/StateLaws</a>.

#### **Making Conscious Disclosure Decisions**

#### A. Online

Most of us have an online footprint that includes activity on social media platforms, blogs, websites, and any other place that information about you is posted online. Collectively, this can be referred to as your "online brand."

Using social media platforms and online tools can be very helpful as a source of information and support. However, it is important to remember that disclosing a cancer diagnosis online makes the information public, and many employers search social media platforms and the internet in order to research job applicants and employees. Therefore, if you are concerned about disclosure, there are some options that provide greater levels of privacy and allow you to only invite certain people to the conversation, such as <a href="Mylifeline.org">Mylifeline.org</a> and <a href="CaringBridge.org">CaringBridge.org</a>.

## B. With Family, Friends, Co-Workers, and Others

Once you decide who to share your diagnosis with, you need to tell them your preferences around what you are choosing to disclose, so that they won't share your information with others against your wishes.

These disclosure decisions can also come up when a family member or a friend wants to host an online fundraiser on your behalf. While crowdfunding may be a useful tool to cope with the financial burden of a cancer diagnosis, there are some possible ramifications everyone should consider before starting a campaign. For more information: Quick Guide to Crowdfunding (TriageHealth.org/quick-guides/crowdfunding).

#### C. At Work

Whether you already have a job or are looking for a job, you need to make some decisions about what, if anything, you will share at work. Making educated, proactive decisions around disclosure is one way to regain some of the control you may have felt you lost when you were diagnosed.

#### 1. Resources To Help You Make Disclosure Decisions At Work

**Your Health Care Team:** It is important to have an honest discussion with your health care providers about how much information you would like shared with your employer if you are asking them to complete medical certification forms when you are asking for a reasonable accommodation or FMLA leave. If you aren't clear with your health care team about your wishes, they may unintentionally disclose more than you wanted.

**Your Employer:** Your employer may have an employee handbook, or some version of a policies and procedures document that describes the employer's human resources policies. Your employment contract (if you have one) may also describe some of your rights and options. Depending on your comfort level, you can ask your supervisor or a human resources professional at work for assistance with getting and completing medical certification forms.

This resource can assist with making disclosure decisions: mn.db101.org/documents/disclosure decisions1.pdf

## 2. Legal Protections At Work

#### What is my employer allowed to ask & when?

Prior to receiving an employment offer, potential employers are not legally allowed to ask any questions about your medical condition or general health.

After a job offer has been made, employers are allowed to ask you questions about your health history or to complete a medical exam, but only if they would be required of anyone entering a similar job. Furthermore, employers are not allowed to take back the job offer based on the results of a medical exam, unless the results show that you cannot perform the essential functions of that job, with or without a reasonable accommodation.

Once you are working for an employer, you can only be asked to complete a medical exam or questions about your health history, when it is "job-related and consistent with business necessity" or if there is a "direct threat" (e.g., requiring an eye exam for a school bus driver).

## What Do I Have To Tell My Employer About My Diagnosis?

In general, you are not required to share your diagnosis with an employer or potential employer. This means you can make conscious decisions about if you want to share your medical information in the workplace, how much, and when. There are times when you may need to share some medical information with your employer:

- If you want to use the ADA or state law protections against discrimination, the employer must be provided some information about your medical condition.
- If you are requesting a reasonable accommodation under the ADA or state law, you will need to explain why such an accommodation is needed.
- If you are requesting FMLA leave, you will need to explain why the leave is necessary.

## What information is my employer entitled to if I ask for reasonable accommodations or FMLA Leave?

Your employer is entitled to a medical certification from a health care provider to show why you are eligible for a reasonable accommodation or FMLA leave. However, your employer doesn't necessarily need to know about your cancer diagnosis if you don't want to share that information. If you are concerned about disclosing your diagnosis with your employer, there are options for protecting your privacy. Your employer only needs as much information as necessary to show that you are eligible for a reasonable accommodation or FMLA leave. In the context of cancer, it is often the side effects from treatment that cause a need for a reasonable accommodation or medical leave, rather than the cancer diagnosis itself. So, if you are asking for a reasonable accommodation due to neuropathy or fatigue, you could talk about those medical conditions without referring to the cancer diagnosis.

Although the U.S. Department of Labor has a model medical certification form that employers may use for employees requesting FMLA leave, many chose to create their own forms. Unfortunately, some of those forms ask for more information than the employer is entitled to. If you are concerned about disclosure, you could ask your health care provider to complete the model form instead of the employer's form, in that case. To view the model forms, visit

- Certification of Health Care Provider for Employee's Serious Health Condition under the Family and Medical Leave Act (dol.gov/sites/dolgov/files/WHD/legacy/files/WH-380-E.pdf)
- Certification of Health Care Provider for Family Member's Serious Health Condition under the Family and Medical Leave Act (dol.gov/sites/dolgov/files/WHD/legacy/files/WH-380-F.pdf)

Even the model FMLA form asks for the health care provider's specialty. So, if you are concerned about disclosure, be deliberate: instead of giving the form to your oncologist, give the form to another member of your health care team, who can provide the necessary information, such as your primary care doctor. Under the FMLA, these providers are permitted to complete the FMLA form:

 Doctors of medicine or osteopathy, podiatrists, dentists, clinical psychologists, optometrists, chiropractors, nurse practitioners, nurse midwives, clinical social workers, Christian Science practitioners, or any health care provider recognized by the employer or the employer's group health plan's benefits manager.

Note: employers aren't allowed to ask you for copies of your medical records when you are making a request for a reasonable accommodation or FMLA leave. Any information that the employer does receive about your medical condition, such as a medical certification form, should be kept in a separate file, not in your regular employee file. Your medical information must be kept confidential.

## Can my employer contact my health care team?

Under the ADA, your employer should not contact your health care provider, without your express permission.

Under the FMLA employers may contact the health care provider who completed the medical certification form, so long as the employee's direct supervisor is not the one contacting the health care provider. However, the employer is only allowed to ask the health care provider for clarification (e.g., what does line 2 say) or authentication (e.g., did you sign the form) of what is on the certification form. The employer is not entitled to additional information than what is included on the certification form.

## If I choose to disclose my diagnosis, when should I do so?

### When asking for a Reasonable Accommodation

Generally, you should ask for a reasonable accommodation when you realize that you need one to effectively complete your job responsibilities. If you delay the request and your job performance suffers, your employer may make a decision to let you go based on your poor job performance. But you may be able to avoid this situation, if you ask for a reasonable accommodation to help you effectively complete your job responsibilities.

## When requesting FMLA leave

Employees should request FMLA leave as soon as they know they need time off work. If the need for leave is foreseeable, employees must provide their employers with at least 30 days' notice. For example, if you know you need surgery in two months, you should request leave within the next month. If the need for leave is unforeseeable, employees must provide their employers with notice "as soon as practicable." This generally means providing notification to an employer within one to two business days of when the need for leave arises. For example, you are experiencing side effects from treatment, go to the emergency room and end up being admitted to the hospital. You suspect that you will miss work for the next few days. You should call your employer as soon as you are well enough to let your employer know you need FMLA leave.

## Are There Other Places I Should Be Concerned with Unintentional Disclosure?

If you are concerned about disclosing your diagnosis, there are a few other places you may want to think about how your information is available. For example, many prospective employers do credit checks as part of the hiring process. If your credit has suffered as a result of medical debt, you should be aware of that and prepared to answer questions around that.



Online fundraisers (otherwise known as "crowdfunding") have become very popular over the last few years as a way to help raise funds for individuals coping with cancer. However, it is important to remember that these fundraisers are typically searchable by name in online search engines like Google.

Specific to the work context, remember that most employers legally "own" your work voicemail, email, and computer equipment. So, if you are concerned about disclosure in the workplace consider using personal voicemail or email for communication from your health care providers.

Finally, some employers have been asking for access to employee's personal social media passwords. Many states have begun to address this legislatively see <u>TriageCancer.org/StateLaws</u> for more information about your state.

#### What types of questions should I be asking when considering disclosing at work?

- Will my diagnosis affect my ability to do the job?
  - o What is my proposed treatment schedule?
  - What are the likely side effects of my treatment and when are they likely to occur?
- How will my diagnosis be "visible" in the workplace, if at all?
- Will I need any special accommodations at work?
- Will I need any sort of medical leave time?
- What are my financial worries?
- What are my insurance worries?
- What laws might protect me?

- What are my employer's policies?
- How will disclosure affect my relationship with my employer and with my co-workers?
- How will disclosure affect my comfort level at work?
- What is the reputation of this employer toward employees in a similar situation?
- Do I plan on staying with my current employer for a long time?
- Do I want to explain my diagnosis to a future employer?

For more information, explore our Employment Resources: <u>TriageHealth.org/employment</u> and <u>CancerFinances.org</u>.

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