Patient Handout: Minor Symptoms in Long-Term Survivors

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Long-term survivors may experience distress while deciding what to do about minor symptoms (see "How to Address Minor Symptoms in Long-Term Survivors;" Sept. 25, 2016). One way to help minimize their distress—and the risk of delayed diagnoses—is by alerting them to the challenges of minor symptoms and by offering tips. Feel free to edit this handout to reflect your practice philosophy and staffing needs.

Dealing With Minor Symptoms

Dear Patient,
This handout will make it easier for you to know what to do if you develop a minor symptom. By minor symptom, we mean a change or problem that doesn't interfere with your life. You can easily hide minor symptoms from other people. You can often ignore them. Examples include a mild ache, a slight decrease in stamina or strength, or the subtle swelling of a limb.

Why do minor symptoms matter?

While not alarming, minor symptoms matter because:

- They may be due to a condition that requires medical attention.
- Over time, they may impair your quality of life.

Why might you have trouble deciding if your symptom is significant?

If the symptom is new and unfamiliar, you may not know what to think about it. Or you may have voiced your concern, and other people (maybe even doctors not trained in survivorship) dismissed your symptom as insignificant and your concerns as being overblown.

Another challenge may be that you're good at ignoring minor symptoms. If you're living with aftereffects of cancer treatment, such healthy denial enables you to enjoy life—as long as each symptom has already been evaluated and treated. When it comes to new symptoms, just because you can ignore them doesn't mean you should.

To complicate matters, the mind can play tricks. Maybe in the past you developed a mild ache after learning about a spot on your scan or, conversely, you had a mild ache resolve after finding out your scans were normal. Simply paying attention to a minor symptom may make it seem worse.

What should you do if unsure about the significance of a symptom?

In general, a reasonable approach is to give yourself a target date—say, a week or two—to call us if the symptom persists. Forget about the target date and call us now if the symptom worries you or if it gets worse (even if you can still tolerate it). Over the phone or in the office, we'll make an informed decision together about the best next step.

What if online resources reassure me I have nothing to worry about?

Always keep in mind that websites and commenters on blogs cannot assess your particular symptom in the context of your personal medical history and current condition. Learning about your symptom from reputable sites is great, such as the National Institutes of Health (www.nih.gov) and the National Cancer Institute (www.cancer.gov). Beware the dangers of taking medical advice from someone who has not evaluated you and is not responsible for your welfare.

Why might you struggle when deciding whether to call about minor symptoms?

You may feel a tension between wanting to avoid a false alarm and wanting timely treatment for a more serious medical problem. Put another way, you don't want to call with something that just needs more time to resolve, and you don't want to delay too long and miss the chance to cure a problem. In addition, you may be tempted to not report minor symptoms because

- You don't want to complain.
- You want to avoid upsetting news.
- Your work and/or home responsibilities feel like higher priorities.
- Your symptom seems insignificant, compared to prior illness.
- You are too weary from ongoing illness to worry about a minor symptom.
- Financial constraints push you to tough it out with minor symptoms.

It's natural to want to avoid the medical scene. Since minor symptoms don't need relief, delaying evaluation is an appealing option. It fulfills any desire to avoid (at least for a while) the inconvenience, discomfort, expense, and emotional stress of doctor visits, needle sticks, scans, waiting for results, worrying loved ones, sense of loss of control, and everything else that goes with evaluating a symptom. Those emotions can influence your rational assessment of whether to report a minor symptom.

How can you overcome your reluctance to report a minor symptom?

Focus on our shared mission: Ensuring you receive the best care, with hope of achieving the best possible outcome. You help us provide the best care by reporting persistent symptoms, no matter how minor. And the sooner you report a symptom, the sooner you benefit: either by ending needless worry or by starting needed treatment.

What if you'd rather wait than risk a false alarm?

Here's the thing: False alarms may be unavoidable if we need diagnostic tests to clarify the significance of your symptom. People who try to avoid false alarms take the risk of delaying the diagnosis of a problem that needs treatment now. More than you want to avoid a false alarm, you want to avoid missing the chance to improve the outcome.

What if you feel you can't afford a false alarm?

Please tell us if it's a hardship to come in for an evaluation, such as if you:

- can't afford more medical bills;
- risk your job by taking off time for a doctor's visit;
- must fulfill childcare or eldercare responsibilities; or
- have transportation problems.

If we know the hardships you face, we can better help you get the care you deserve.

Minor symptoms are no small matter. Proper medical attention for minor symptoms helps you live as fully as possible today, tomorrow and every day. OT

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