

Examples of written answers on  
moderated web forums that  
would be difficult for health  
illiterate patients to understand

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- We are not commentating on the accuracy of the answers provided by health professionals to the questions on the following pages.
- What we are doing is looking at the answers on the following pages through our experience as a heart patient and carer and the broader health illiteracy lens, including our extensive experience with other patients.
- In our experience on many patient forums, there are patients who can give the impression of health literacy by ‘parroting’ medical terms and medication names they have ‘googled’ but deeper reading of their questions shows that they don’t actually understand the topic and any answer should reflect that lack of understanding.
- Patient questions that indicate possible anxiety and depression need to be sensitively dealt with including urging follow up with professional help.
- Don’t forget that a digital human health coach is about conversation, and this provides the opportunity to explore if the patient understood the answer and allows an opportunity for rephrasing if required.
- Ideally, any forum should always refer patients to their doctor (or EMD if urgent) for follow up.

05/20/2018



how can I prevent a stroke?

view answer ▾

Primary prevention of a stroke occurs by identifying your personal stroke risks and eliminating or minimizing them. Genetics and age cannot be altered. However, high blood pressure control and smoking cessation are pivotal in reducing stroke. Diabetes mellitus should be identified and optimized. A diet low in fat and salt and rich in fruits and vegetables seems to add years to a life. Daily exercise and optimal weight are also recommended.

If you have had a stroke, TIA or have certain high-risk conditions such as atrial fibrillation or congestive heart failure medications can be taken daily that reduce your stroke risk. Aspirin reduces the risk of a recurrent stroke by 20%. Other antiplatelet medications can be taken as an alternative to aspirin and have similar benefit. The group of medications known as “STATINS” that lower cholesterol reduces stroke recurrence. If you have atrial fibrillation, anticoagulants such as warfarin may be used to lessen your stroke risk. Newer substitutes for warfarin exist that can be used as an alternative in certain circumstances.

Several surgical procedures have been devised that reduce stroke risk. An operation on a carotid artery when symptomatic and severely narrowed may be offered to reduce stroke. Carotid stenting can also be done to alleviate risk in certain individuals. Cerebral aneurysms when identified can be surgically isolated through either direct and indirect methods to minimize their risk of rupture.

Thank you, Dr. Joseph Hanna

A more succinct and easier to understand response could be:

Your family doctor can help with advice on preventing a stroke. They will ask you some questions and might send you for some tests to see if you have a risk of stroke. If you do have a risk, they will talk to you about medications and lifestyle choices such as diet, exercise and quitting smoking that can help prevent stroke.

10/19/2018



**My husband has Familial Hypercholesterolemia, and I have high cholesterol, but the doctor says it is not the same, why?**

[view answer](#) ▾

Cholesterol can be high for a lot of reasons. Lifestyle can play a large role, some medications increase cholesterol levels, some diseases can increase cholesterol levels (for example certain types of kidney disease and thyroid disease). Familial Hypercholesterolemia is different in that it is an inherited disease that leads to very high cholesterol levels starting very early in life. In most patients, FH is inherited as an “autosomal dominant” disease, i.e. a child of an affected parent has a 50/50 chance of inheriting Familial Hypercholesterolemia. You should discuss this further with your physician and you may find the website of the FH Foundation helpful as well. Thank you for this question.

A more succinct and easier to understand response could be:

Familial Hypercholesterolemia is high cholesterol that is inherited from your parents and grandparents. High cholesterol in general can be caused by lifestyle choices such as what you eat, and sometimes by other diseases and medications. Your doctor can help you and your husband with lifestyle recommendations and medications to lower your cholesterol and risk of heart and other diseases.



MelissaLynn, *SUPPORT NETWORK Member Asks*



"Hello this journey is new and most of all SCARY. I ask a lot of questions and sometimes i feel as if i offend the doctors. How do i ask the questions necessary for my understanding with out the backlash of the concern of them not giving proper care to my mother. I wanna run away a lot!!!!"



Having more and better information may help you feel less scared. Th doctors shouldn't be offed by your questions. You deserve all the answers you're seeking to learn more about your mother's condition and how best to help her! I suggest that you write the questions down and either hand them to the doctor during your mother's next medical visit or mail them to the medical office prior to the visit. For a variety of reasons, doctors are more likely to provide answers if the questions are in writing. If the doctor feels too busy to answer you, then he or she has the responsibility to have a nurse or other staff member work closely with you. Please don't just back off and go silent. Your mother needs you to advocate for her! —Barry J. Jacobs, Psy.D., AHA volunteer and co-author of AARP Meditations for Caregivers

This answer is ok but maybe try:

Doctors aren't offended by questions, but it can be hard for them to answer a lot of questions in a short appointment and if there are other patients waiting. If you can, write down your questions and send them to your doctor a few days before your appointment so they have time to prepare answers for you. If you can, book a longer appointment so you aren't rushed. You should never worry about the care your mother will receive just because you ask questions.



**MELM22**, *SUPPORT NETWORK Member Asks*



"Hi there, my name is Mel and I'm 35 years old , I suffered from a stroke 1 month ago and I have just got out of the hospital. I'm looking for a bit of support and guidance getting back towards living a quality life again . Thank you for your time , Mel"



Community support is typically available in most communities to improve reintegration into society after an illness. Your hospital's social services department will likely have a list of organizations with interest in stroke recovery in your community. If this does not suffice, call your local American Stroke Association chapter and ask if they have any leads for community support. You should also be integrated into a rehabilitative program with the goal of returning to the previous level of engagement. Thank you, Dr. Joseph Hanna

This answer is ok but maybe try:

If you can attend your hospital's stroke rehabilitation program you will learn a lot about returning to a quality life. Also, talk to your hospital's social services department about community support from local organizations. If these aren't available in your area you can try the American Stroke Association website to see if they can offer advice in your area.



**frecoll22**, SUPPORT NETWORK Member Asks

**Q.** "I had cardiac ablation 7 days ago. Now I'm crying and so tired. Is this normal?"

**A.** I have had patients who have had some changes to their energy level and mood-related to sedation medication given for a procedure, but 7 days out seems a bit far unless you were taking pain medication after discharge. It is also possible that you may need some of your cardiac medications adjusted, as they were prescribed before the ablation. Make sure that you follow up with the doctor who did the procedure as well as your regular cardiologist and PCP. Thank you, Nurse Tessa

This answer is ok but maybe try:

*Some patients can be a bit sad and tired for a few days after a heart procedure but if it keeps going you need to see your doctor for advice. They can change your medications if need be and talk to you about other reasons for being tired and upset. They can also arrange for some counselling to help manage your mood.*





**OneOmega**, SUPPORT NETWORK Member Asks



**"Why when speaking with my physicians (prime, cardio, nehp), QOL discussions rarely include anxiety, depression and isolation, why? This has got to be as important as the count of steps or grams of sodium."**



You make an excellent point. Exercise and diet are very important for managing heart disease and for ensuring a high quality of life. But social isolation, anxiety and depression are also associated with decreased quality of life and must be addressed as assiduously as lifestyle modifications. I suggest you raise these emotional concerns directly with your physicians. I don't think they will dismiss your questions, though they may feel more comfortable referring you to a mental health professional to best address them. Be your own best advocate and bring up what most matters to you, rather than only what your physicians ask about.—Barry J. Jacobs, Psy.D., AHA volunteer, co-author of AARP Meditations for Caregivers

This answer is ok but maybe try:

You are right that emotional support is important to prevention of diseases and recovery from any events or surgeries. Physicians refer patients who need emotional support to mental health professionals who have the time and tools to help patients. You should talk to your physician about any concerns you have, and they can ask a few questions to decide who can best help you.

06/01/2018



i am trying as hard as i can to rehab but not much going on.i think i am getting depressed from lack of progress. any thoughts

[view answer](#) ▾

Good afternoon, Successful Stroke rehabilitation can depend on several factors such as Physical factors including the severity of the stroke both cognitive and physical effects. Emotional factors such as motivation and mood, and the ability to stick to rehabilitation activities outside of therapy sessions, social factors such as the support you might have with friends and family and the therapeutic factors such as the skill of your stroke rehabilitation team. Thank you, Dr. Latonya Law

This answer is ok but maybe try:

If you are still attending your hospital's rehab program talk to one of the rehab staff about your concerns. A lot of patients feel the same way as you and the staff have experience from helping them. Recovery and rehabilitation take time and practice. Professional athletes can take months to recover from a surgery even though they are young and fit so don't be hard on yourself. If you are feeling depressed about your progress talk to your doctor as soon as you can so that they can get you some extra support.