



Advocacy & Services  
for LGBT Elders

**We refuse to be invisible**

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Going to the doctor or seeking medical care for even minor issues presents unique challenges for LGBT people. The decision to ‘come out’ to your provider, concerns about their reaction and approach if you do come out, or the possibility of receiving substandard care, are often top of mind. The path to securing adequate insurance coverage, researching options, and overcoming hesitation or fears of mistreatment can be overwhelming for many people.

LGBT communities are resilient and have a history of creating change through large and small efforts. Advocacy is an important tool LGBT people have in securing and managing quality healthcare. For our purposes, advocacy is the process of getting your healthcare needs met through four actions: preparation, communication, cultivation, documentation.

**How do you know you need advocacy?** Everyone can benefit from advocacy. Common situations would include when you are dealing with a major health issue such as a surgery, injury or chronic illness treatment. However, there are other situations where advocacy can have a major impact on your health. For example, if your doctor doesn’t make eye contact or examine you thoroughly, or if you always feel rushed during appointments. Other indicators may be poor communication and responsiveness on the part of your provider, e.g. difficulty getting prescriptions or orders, or not getting calls back regarding your concerns. In addition, if you are feeling forgetful, unsure of what questions to ask, or if you want to be sure you’ve understood everything correctly advocacy can help.

Whether advocating for yourself or someone else, the benefits are numerous. On an individual level, taking control of your health can be empowering. Understand that you are a consumer of healthcare and should expect a high-quality experience. Many people grow up with the idea that the doctor or provider is the ‘expert’. No one has more experience living in your body than you, it’s important to recognize that you and your providers are in a collaborative relationship who each bring knowledge and expertise to the table.

**Preparation.** In order to advocate successfully for yourself or another person, prepare as best you can. Think about what you need to bring, what

needs to be planned, and what you want to accomplish during the appointment. Try to keep a list of questions on your phone or in a notebook between appointments to make sure you don't forget important topics.

It is also incredibly important to bring your current pill bottles or an accurate list of medications to all appointments. Your doctors aren't usually in the loop about any medication adjustments made by other providers or the vitamin and nutritional supplements you may be taking. Make certain to plan ahead for transportation, bring water, meals, and snacks in case of long wait times. If you've had a recent hospitalization or discharge from a rehab facility, it is a good idea to bring any relevant paperwork for your doctor to review.

For LGBT older adults, bringing a loved one to the appointment with you is a critical act of advocacy. Inviting another person into the room often changes the dynamic with the provider. Having a friend present helps decrease your anxiety and ensure no opportunities for questions or dialogue will be missed during the appointment. Especially in today's healthcare settings where the visits can be brief and the provider is often entering information into the computer while talking with patients, having a second set of eyes and ears is vital. Many people don't ask friends to accompany them due to not wanting to feel like a 'burden' or 'trouble', but that thinking undermines our health in the long-term. Inviting your loved ones to play a practical role in your health can strengthen your relationship and improve health outcomes.

**Communication.** The basis of any good relationship is communication. The same is true of your relationship with healthcare providers. If you are able to articulate your needs and expectations clearly and in a respectful manner, you are more likely to have them met. Advocating in this way ideally should happen at the beginning of a relationship and be reinforced over time.

For example, when searching for a doctor you can approach the first meeting as an 'interview' to see if that doctor is a good fit for you. You might start the conversation by saying something like this: 'It's so nice to meet you doctor, thank you for your time. I'm here because I am looking for a new geriatrician who is willing to take the time to really communicate with me. I also want to be sure that my geriatrician will advocate for me if I'm in the hospital. Can you share a bit about your experience and approach in these areas?' If you are comfortable, you might also ask about your doctor's experience in working with LGBT people.

If you have a long-term relationship with your provider already but want to improve the experience you could say something like: 'We've known each other for a while and I appreciate our relationship. I anticipate my health needs increasing in the coming years and would like to have a conversation to be sure we're on the same page, would you be open to that?'

The final piece of communication is to provide your healthcare team with any advance directives you may have such as a Do Not Resuscitate Order (DNR), Practitioner Orders for Life-Sustaining Treatment (POLST) form, or Power of Attorney (POA). In addition, your health provider should have you sign a HIPAA release form that approves who they can share your medical information with. It's a good idea to include your health care POA and/or person(s) who attend appointments with you on the HIPAA list.

As the HIPAA form indicates, you have a right to privacy and confidentiality regarding your medical records. Confidentiality of information shared in medical records can be a concern for LGBT patients concerned with being “outed” in the health care system. You can request to see a copy of medical chart and the information that is being shared. It may be helpful to have a conversation with providers about any concerns you may have in sharing information related to your current or past medical team. If you at any time you believe your health information has not been protected, you have the right to file a complaint with the provider, insurer and with the U.S. Department of Health and Human Services. Learn more here: <https://www.hhs.gov/HIPAAa/filing-a-complaint/complaint-process/index.html>

**Cultivation.** Another critical component to your healthcare experience are the nurses, medical assistants, receptionists and other professionals who make up the team. Whenever possible, try to establish positive relationships, get to know their names and make sure they know yours. Recognition breeds reaction, if you call in or need a task completed, a person who knows you is more likely to move quickly.

In a healthcare setting, providers see a lot of people who are sick - which can translate into irritability and frustration on the part of the provider and the patient. To cultivate a positive relationship, take time to notice and express appreciation for the work the healthcare team is doing. Saying thank you, or even a thank you note goes a long way to maintaining a positive relationship. You could also post a positive review online and let the team know you thought enough of their work to do so. Healthcare is powered by people, and cultivating positive relationships will help them be invested in your health and well-being.

**Documentation.** The electronic medical records (EMR) systems that most health institutions use are a wonderful resource to manage your healthcare and advocate for yourself. You should have access to any labs, testing, visit summaries, and other notes from your doctor. Don't be intimidated by the medical language, take the time to review your information. In appointments providers often use shorthand to record lab and test results. There's a great deal more information in those documents that can be of use to you. It is okay to ask your doctor to explain what the information means.

If you are not online or would prefer to maintain independent records, ask for printed visit summaries at the end of every appointment. You can also request paper copies of labs and any additional testing that has been done. Remember the list of questions we recommended you keep earlier? It's a good idea to have a 'health journal', a notebook with all of your personal notes about your appointments.

We also recommend maintaining a health history document. This can be in the notebook or an electronically stored record of any major health issues, surgeries, medication changes, etc. Tailor it to your needs and level of specificity.

So maybe you've tried all of the above and you feel like your approach isn't working, what can you do? If your provider has, through words or actions, indicated that they can't meet your expectations, it may be time to look for a new provider. Your health is of the utmost importance and you deserve to have a strong ally. If you are looking for an LGBT affirming provider, you can begin by searching the provider list through the Gay and Lesbian Medical Association at [www.glma.org](http://www.glma.org).

In areas where you might have limited options or limited specialists, your approach may need to be adjusted. For example, making certain you always have a friend with you in appointments or hiring a healthcare advocate are strong next steps you can take. Contact your local SAGE Affiliate, LGBT health center, or LGBT community center to find out what additional services are available in your area. Your friends and family can also help provide referrals to health professionals they trust. If you feel you have been the victim of discrimination, reach out to organizations like Lambda Legal, National Center for Lesbian Rights, and Transgender Law Center may be able to provide advice and support.

***Advocacy is a powerful strategy for taking control of your health.*** You and your loved ones deserve relationships with healthcare providers built on shared expectations, trust, and understanding.

#### Additional Resources

Center Link – [www.lgbtcenter.org](http://www.lgbtcenter.org)

GLMA - [www.glma.org/](http://www.glma.org/)

Lambda Legal [www.lambdalegal.org](http://www.lambdalegal.org)

NCLR – [www.nclrights.org](http://www.nclrights.org)

National Resource Center on LGBT Aging – [www.lgbtagingcenter.org](http://www.lgbtagingcenter.org)

Rad Remedy – [www.radremedy.org](http://www.radremedy.org)

SAGE [www.sageusa.org](http://www.sageusa.org)

Transgender Law Center – [www.transgenderlawcenter.org](http://www.transgenderlawcenter.org)

The Care Plan – [www.the-care-plan.com/](http://www.the-care-plan.com/)

*About the author: Jacqueline Boyd, founder of [The Care Plan](#), is a long time aging specialist and LGBTQI advocate. Jacqueline's passion for health and aging started when she was a Certified Nursing Assistant in college. Working in nursing homes gave her a deep appreciation for the struggles many face throughout the aging process.*