

Create Your Care Plan



AN LGBTQ PERSON'S
GUIDE TO PREPARING
FOR MEDICAL PROCEDURES

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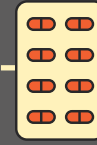
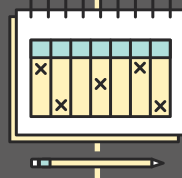
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Introduction

Welcome to *Create Your Care Plan: An LGBT Person's Guide to Preparing for Medical Procedures*. This guide is a practical tool for lesbian, gay, bisexual and transgender (LGBT) older adults and others who are facing surgery or another medical procedure, and need or want to take control of planning for their own care. By the time you finish this guide you will be able to create your own care plan, which in turn will help you to have the most successful recovery possible.

Undergoing a surgical or medical procedure can be one of the most difficult times in a person's life. Typically, people rely on family members to help them through the process and manage their care. But what if you don't have family members who can step into that caregiving role?

LGBT older adults are less likely to have children, more likely to be single, and may not have good relationships with their

Ask yourself: As you recover from surgery or a medical procedure, who will take care of you?

If the answer is not obvious, this guide is for you.



families of origin.¹ Many form **families of choice** to rely on, made up of close friends and perhaps a partner or ex-partner. They may be a strong support network, but their role in your care may not always be clear. Ask yourself: as you recover from the procedure, who will take care of you? If the answer is not obvious, you are not the only one. That's why we created this guide.

¹ *Out & Visible*, SAGE, 2014

A NOTE ON TERMINOLOGY

The acronym LGBT in this guide represents a full variety of gender identities and sexual orientations. Queer, questioning, gender expansive, intersex, non-binary individuals and more are included in our understanding of LGBT communities.





Health care providers have a tendency to make decisions about patient care based on best practices, without fully considering the patient’s needs and wants. Proactive care planning allows a patient to take charge of their own health by identifying their personal health goals and prioritizing what is most important to them, thereby ensuring that their health care wishes are respected.”

JANE FIALKO, LMSW

E-LINC SOCIAL WORKER, SAGE, NEW YORK CITY

We know that many LGBT older adults have smaller support networks than their non-LGBT peers, and that their families of choice don’t always look like typical families. We also know that LGBT people may be nervous or reluctant about interacting with the medical world, based on past experience or a fear of being treated poorly. Unfortunately, LGBT communities experience higher rates of chronic illness, and are more likely to suffer from a number of health conditions.² When you’re faced with undergoing surgery or a medical procedure, we want to help make the process as easy as possible.

A smooth recovery begins with knowing what to expect, which you’ll read about in Section 1. It continues with building and engaging your support networks, which is the focus of Section 2. You may not think you have anyone who can help, but this guide will help you to think through possibilities and find ways to engage people you may not have considered in your care team. It can be daunting to ask

others to care for you, but it is our hope that the tips and processes laid out in this guide will make it possible for you to do just that.

LGBT people have an opportunity to think creatively about health and wellness. Whether you’re undergoing surgery to affirm your gender, replace your knee or begin cancer treatment, you will need assistance afterward, and planning ahead will help your recovery go more smoothly. The tools and resources in this guide can help you to put a care plan in place that meets your needs, in order to give yourself the best chance of a full and successful recovery.

CARE TEAM:

The friends, family and acquaintances who actively participate in the care of an individual. Often the care team coordinates to address post-procedure needs such as meal preparation, medication reminders, housekeeping, transportation, and companionship.



² *Improving the Lives of LGBT Older Adults*, Movement Advancement Project & SAGE, 2010



What to Expect

Medical Providers

If you have been through previous procedures or spent time in a hospital, it will come as no surprise that there are many people involved in your medical care. The medical team from the time of diagnosis through your recovery may include:

- Primary Care Physician (PCP)
- Specialist or Surgeon
- Consulting Physicians (anesthesiologist, orthopedist, etc.)
- The “right hand” of your PCP and specialist—typically a Nurse, Physician’s Assistant or Medical Assistant—who can answer questions and will coordinate appointments
- Hospital Staff (Hospitalist, Residents, Fellows, Nurses, Nursing Assistants, Lab techs, etc.)
- Discharge Planner (Social Worker or Nurse who coordinates your discharge from the hospital)

The **primary care physician (PCP)** is the center of your medical team. This doctor can offer referrals, recommendations,

and a perspective on how this procedure will affect your overall health. It is important to continue to see your PCP throughout the course of your procedure and treatment, even though you may have many appointments with other doctors. In some cases, you may have increased visits with your primary care physician to more closely manage specific health conditions.

The **specialist** is the person who will be most knowledgeable about your condition and treatment options. Typically, your PCP will make the referral to a trusted specialist for the procedure. Depending on the area of medicine, the specialist may be the one to perform the procedure, or may refer you to another specialist or surgeon.

When there is time to plan ahead for a procedure, you have a significant advantage in finding the right medical options for you. The first step is to research your condition and understand expectations about the procedure and recovery. Be sure to use reliable sources (ask your doctor if you’re not sure where to look), and keep in mind that some of the information you find may not pertain

QUESTIONS TO ASK YOUR DOCTOR



Here are some questions you may wish to ask the specialist during the initial consultation:

- How many times has the specialist performed this procedure? How many of these procedures do they complete each year?

- How is “success” defined for this procedure, and what is the overall success rate? What is the specialist’s success rate?

- Can you see examples of their work? (This is not always relevant, but is critical to many people if the effects of surgery will be visible, such as scarring.)

- What hospital or facility would the procedure take place in?

- Are there reasons not to do the procedure?

- What are the risks associated with the procedure?

- What other options might there be to resolve the issue (less invasive procedures or alternate forms of treatment)?

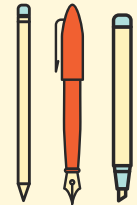
- What is their knowledge about the course of healing after the procedure?

- What should you do to improve chances of a successful recovery?

to you. Verify what you learn with someone from your medical team before using the information to make decisions.

If you are feeling uneasy about the procedure or uncomfortable with the specialist, consider seeking a second opinion. Each medical provider is unique in their level of experience and training. In sparsely populated areas there may only be one or two options, but in more densely populated areas there could be hundreds of providers available.

If you feel uncomfortable, consider seeking a second opinion.



It is important that you feel comfortable with your medical team, so it may be worth the time to find medical providers who are LGBT-affirming. For information and tips on finding LGBT-affirming providers, see page 10.

Gender Affirming Surgery

When planning for a gender affirming surgery, the careful selection of a provider is critical. Knowing how many times the specialist has performed the procedure is particularly important, as these

numbers vary widely and can give you a general sense of the specialist's comfort level and proficiency. Ask if the surgeon follows WPATH standards (see below), and if the hospital staff and eventual rehabilitation center have been prepared or trained to work with transgender patients. Other common concerns are location, length of time in the hospital and clarity on billing and insurance coverage. For more information about gender affirming surgeries, see the publications listed under *Resources*.

STANDARDS OF CARE

The World Professional Association for Transgender Health (WPATH) is a nonprofit organization that establishes internationally accepted Standards of Care for the treatment of transgender people, including gender affirming surgeries. You can find lists of registered providers and other resources on their website, WPATH.org.



Medical Preparation

Once you have decided to undergo the procedure, you will typically be required to complete tests to make sure that you are medically ready for the procedure. This process is critical to ensuring that you do not have any underlying conditions that may affect the outcome of the procedure.

Office staff can be helpful in providing an additional perspective on the procedure. Ask to speak with the registered nurse (RN) or care coordinator. Because the specialist splits their time between surgery and the office, the RN often fields calls from patients with questions and concerns. They can offer practical tips and advise you on what the procedure and recovery will be like.

If you have insurance, your insurance carrier should also be consulted to ensure that the costs of the procedure and specialist will be covered. If you are concerned about paying your portion of the cost, consider speaking with your insurance company and the billing department at the facility. Many hospitals are structured as non-profits and are able to offer subsidies, vouchers, or other adjustments to minimize your out-of-pocket costs.

If you're concerned about the cost of your procedure, talk to your insurance company and the medical institution—there may be ways to decrease the out-of-pocket cost.



Following the initial consultation and the completion of any testing, the surgeon will likely want to see you one more time before the procedure. These appointments can proceed very

PREPARING FOR THE PROCEDURE



Medical Preparation Checklist #1

- Research your procedure, the risks and recovery time
- Identify the medical team and location
- Schedule initial consultations with 1–2 specialists
- Choose a specialist for the procedure
- Complete surgical readiness testing and assessments
- Talk with the surgeon’s nurse about aftercare needs
- Confirm insurance coverage for the surgeon and the hospital/facility
- Clarify financial burden and plan for how to pay for the procedure
- Prepare questions for the surgeon (see page 4)
- Complete advance directives (see page 22)

quickly and it may be difficult to retain all of the information the surgeon is sharing. Throughout the process, make sure you understand what the doctors are saying—it’s okay to ask them to slow down or repeat themselves. If possible, bring someone from your care team with you to these appointments to help you ask questions and take notes.

Self-Care

During the process of preparing for the procedure, the importance of self-care cannot be understated. It benefits you to do everything in your power to boost the body’s defenses.

Here are some recommended steps to support a healthy recovery. These are general recommendations—always consult with your doctor if you have questions about what is best for your specific situation:

- Drink water
- Eat foods that are rich in nutrients and minimize fatty, greasy or sugary foods
- Exercise regularly
- Get 8 hours of sleep each night
- Quit smoking, drinking, and using recreational substances before the procedure
- Connect with loved ones

It is important to build in self-care and interactions with loved ones to support your emotional and physical well-being heading into surgery. Discussing concerns and apprehensions with a trusted person in your

life can relieve stress and calm fears. If you are facing an ongoing medical process, or something that is emotionally difficult for you, consider entering into counseling or finding a support group.

FINDING SUPPORT

If you need support, consider reaching out to LGBT-welcoming groups and organizations.

LGBT organizations have resources gleaned from their work supporting people in the local area. Some hospitals and community-based health care providers have LGBT support groups and advocates within their system.

SAGE affiliate offices and the SAGE LGBT Elder Hotline (1-888-234-SAGE) are available to provide peer support and additional resources—see the *Resources* section for more information.



will change into a gown and place any personal items into a designated bag. You will have a chance to speak with your specialist(s), and then it will be time for the procedure.

The specialist will communicate with a designated member of your care team throughout the procedure. It is a good idea to have someone who you have authorized to make medical decisions present during the procedure, in case unexpected decisions need to be made while you are under anesthesia. (See *Advance Directives* for more information about authorizing someone to make medical decisions for you.)

After the procedure you will be taken to a recovery area to allow the effects of anesthesia to wear off. The staff will monitor your vital signs and ensure you are returning to normal. Depending upon the type of procedure, you will then be transferred to another area of the hospital, a rehabilitation center in another location, or be discharged to go home.

When you leave the hospital, make certain you have the following:

- Discharge paperwork
- Written aftercare instructions and restrictions
- Prescriptions
- Special equipment
- Personal items

Before you leave, be sure that you or a member of your care team reads

Day of Procedure

Typically, the doctor's office will contact you the day before the procedure to tell you what time you should arrive. It is advised to have someone drive you to the location and be present for the duration of your time there. Allow enough time for transportation and navigating your way through the facility. Upon arrival, you will check in, sign final paperwork, and then be taken into a private area, where you

THE CARE ACT: KNOW WHO YOU'LL NAME

The Caregiver Advise, Record and Enable Act has been adopted in some form by the majority of states in the U.S. The Care Act requires hospitals to ask patients at admission whether they'd like to designate a caregiver. Once a caregiver is named, the hospital is generally required to record the name of the caregiver in medical records, inform the caregiver when the patient is being discharged, and give the caregiver adequate training on how to perform any medical care needed at home.



Importantly, most versions of the CARE Act have no stipulations about who may be named as the caregiver, which means you can name a friend or chosen family member and that person should be recognized by the hospital as your caregiver. Before you go in for a procedure, give some thought to who you will name as your caregiver, and talk with that person about what this means. Contact your local AARP office for more detailed information about the CARE Act in your state.

through the discharge instructions and understands them thoroughly. Don't hesitate to ask questions or to request more instruction on how to do something that will be needed at home.

Post-Procedure

Following the procedure, you may not feel like yourself for quite a while. It can take weeks or months to heal, and for some procedures even a year or more. The medical team will advise you on what to expect during your recovery.

Pain, fatigue, lack of appetite, lack of thirst, dizziness, and swelling are common immediate effects of many procedures. The medical team will probably provide you with prescriptions to offset some of these effects, but experiences vary by individual.

During your follow-up appointments the medical team will need to know certain pieces of information to assess your healing. Some common areas to monitor are:

- Pain level
- Food/fluid intake
- Drainage/wound care
- Medications taken
- Vital signs
- Bruising/swelling/redness

Listen to your body and if something doesn't feel or look right to you, you or a member of your care team should contact the medical team. There will be follow-up appointments which are not to be missed. These appointments are the specialist's opportunity to check on your healing process, make any adjustments to your care plan and answer questions that may have come up.

Listen to your body, and contact your medical team if you have any concerns.



Your care team is a crucial component of your healing. You may not feel up to having visitors, but you will need some direct care and may need help with tasks like showering, cooking, and cleaning. Be honest with your team about when you are interested in conversation and being active. It is normal to be a bit irritable at times following surgery.

If you are in a hospital or rehabilitation center, nurses and other staff will be on hand to monitor your progress and assist you with most tasks. It is still a good idea to have a member of your care team with you, for reasons outlined in the next section. If you will be recovering at home, you are likely to need additional assistance, and you may be eligible for home care and other services; those specific resources will also be discussed in the next section. If you do not feel that you have enough care in place to recover safely at home, talk to your doctor and the hospital discharge planner about your options. Living alone may be reason enough to qualify for extra services or time at a rehabilitation center.

If you are not comfortable returning home immediately after the procedure or hospitalization, speak with your doctor to determine whether your aftercare can include full-time home care or admission to a rehabilitation center.



PREPARING FOR RECOVERY



Medical Preparation Checklist #2

- Confirm location of recovery
- Confirm estimated length of stay in rehabilitation center, if applicable.
- Confirm anticipated hospital discharge date
- Review recommended aftercare services (home care, skilled nursing, etc.) and determine first/second/third choice providers
- Consider your wishes about hospital visitation (see page 14)
- Learn about wound care and other medical tasks to be done at home
- Review dietary or nutritional considerations
- Ask about home alterations and equipment needs, and take care of these in advance if possible

Special Topic: Choosing LGBT-Affirming Providers

Whether you're choosing a doctor, investigating rehabilitation centers, or looking for a home health aide, it is important to find providers who can be trusted to provide you with competent, respectful care. For many LGBT people, this means finding someone who understands LGBT issues and is comfortable working with LGBT people. Here are some helpful tips for finding an LGBT-affirming provider:

- The best references come from the people you already know and trust. Ask friends with similar circumstances who they have used, and whether they felt respected and comfortable.
- Contact your local SAGE Affiliate or LGBT aging provider, LGBT community center, PFLAG chapter or other LGBT organization and ask for referrals to providers they have worked with in the past.
- Utilize online databases, such as:
 - Medical Facilities**
The Healthcare Equality Index: hrc.org/hei
 - Individual Medical Providers**
The Gay & Lesbian Medical Association: GLMA.org
 - The World Professional Association for Transgender Health: WPATH.org
 - Rad Remedy: radremedy.org
 - Aging Service Providers**
SAGECare: sageusa.care/sagecare-providers
- Reach out to your local HIV/AIDS service providers, who often have close connections to LGBT-affirming home care agencies and other services.
- Look to see if there are providers who advertise in your local LGBT newspapers and magazines (either print or online) or have signed up as sponsors, members, or partners with local LGBT groups.
- Ask whether the provider or the agency's staff have been trained on how to provide culturally competent care to LGBT people.
- Ask providers directly if they serve LGBT individuals, and if so, find out whether that's concrete (current or past clients) or hypothetical ("we welcome everyone").
- Most providers have non-discrimination policies—check to see if these policies specifically include sexual orientation and gender identity, and whether they post or distribute their policies openly. You can also ask how those policies are enforced.
- Most importantly, always trust your instincts! Only you and your loved ones know what's right for you.

Adapted from *10 Tips for Finding LGBT-Affirming Services*,
National Resource Center on LGBT Aging, 2017



Create Your Care Plan

A care plan is a tool for managing your care. In general, a good care plan captures the details of the procedure (including providers, location, medical team, and plans for recovery), any relevant health history and medical information, a list of identified care team members, and a list or chart of tasks to be completed, including how, when, and by whom.

There are 3 basic steps to building and using a comprehensive care plan:

1. **Identify Your Needs**
2. **Confirm Your Care Team**
3. **Implement the Plan**

The next sections will walk you through each of these steps, utilizing the worksheets provided at the end of this guide.

CARE PLAN COMPONENTS



- Your demographics (date of birth, preferred name, address, phone number, etc.)**
- Relevant medical history, medications**
- Procedure details**
- Care team**
- Care calendar**
- Advance directives (see page 22)**

Identify Your Needs

It can be challenging to acknowledge that you will need assistance or support, but it is in your best interest to plan for your needs realistically. As you prepare for and recover from your procedure, there are a number of tasks that may need to be completed by another person, or will be more successful with their involvement. For example, meal preparation: if you are trying to make a meal for yourself but are tired and dizzy, you might stop partway through or make a less nutritious meal than is optimal.

We'll discuss how to ask people to participate in your care plan in the next section. Identifying your needs first

allows you to set aside worries about who will accomplish these tasks, and focus on what will have the greatest impact on your health. Many of the most common needs to consider are listed below:

1. Advocacy at appointments and during the procedure:

Your advocate ensures your needs are met, helps to facilitate clear communication, and can intervene if anything inappropriate occurs during your stay. Having a trusted support person by your side provides moral support and ensures consistent communication with the medical team. It is also helpful to have someone with you whenever you speak to the doctor at appointments and in the hospital, to take notes and be sure you understand everything being said.

2. Equipment pick up or installation: If there are pieces of equipment that need to be picked up for your use, try to arrange for that before the procedure. Basic equipment can be installed by your care team; medical devices or machines may need to be brought to the home and installed by a professional.

3. Transportation to/from the procedure:

You may be impaired or weak following the procedure, and it is important to have transportation home from the hospital or doctor's office. (In some cases, the office may not even allow you to leave on your own, for safety reasons.) If possible, the transportation person should help with getting you into your home and settled after the procedure.

4. Transportation to appointments:

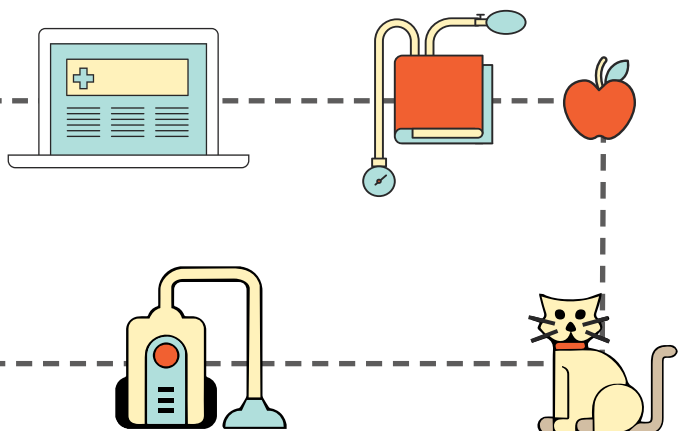
You may be unable to drive or take public transportation alone for some time. Scheduling someone to take you to follow-up appointments ensures that they will not be missed.

5. Housekeeping or housesitting:

Maintaining a clean and uncluttered environment will benefit your recovery, and is another area where care team members can help out. At a minimum, your bedroom, kitchen and bathroom need to be kept clean and sanitary. Housekeeping tasks such as taking out the garbage, dusting and vacuuming are all things you may not be able to do yourself for some time.

6. Pet care:

Any pet care including walks, feeding, litter boxes or other cleaning should be completed by a care team member until your strength returns. You might consider boarding your pets or having them stay in a friend's home while you recover. Having loved ones nearby—including pets—can be beneficial to your mental and emotional well-being, though, so

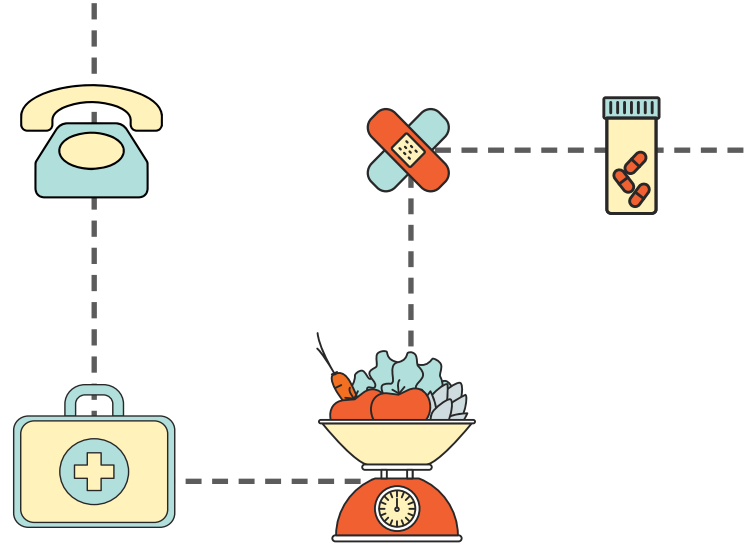


finding someone to help care for them in your home may be more ideal. If you have concerns about being around animals after your procedure, talk to your doctor.

7. Communication with the care team and medical team: Following up with doctors, specialists, other caregivers, and friends and family not involved in your care is a role that you may not be up to post-procedure. A care team member who can answer your phone, send updates, and help communicate with others involved in your care will be extremely helpful.

8. Personal care and safety support: Personal care and safety support refers to *Activities of Daily Living* such as bathing, toileting, feeding yourself, moving around or transferring positions. After a procedure your whole body may be affected and drained from the experience, and you may need assistance to do even the most basic things safely. For more complex procedures, it may be advised that you get help from professional health workers for some or all of these tasks, and these services may be covered by your insurance. If you have friends or family members who have training in this area, they may be the best people to ask.

9. Medication: Adhering to the medication regimen recommended by your medical team is critical to your well-being. Care team members can call in prescription refills, pick up



medications, remind you to take them, sort them into pill organizers, change patches and more.

10. Grocery shopping and meal preparation: Proper nutrition is important to your healing, and members of your support team may be able to contribute meals and grocery shopping services throughout the course of your recovery. A website like mealtrain.com can be helpful for setting up a schedule of meal deliveries. Be sure to communicate any dietary restrictions set by your medical team.

11. Wound care/drains: Wound care should be completed or monitored by a nurse whenever possible, however you may be in a situation where nursing services aren't available. Before you are discharged, a care team member should be trained by the medical team on the process of changing the wound dressing or emptying drains, including frequency, supplies, and what to look for. It is important to know how much drainage is normal and what the appearance should be.

12. Monitoring basic health: During your follow-up appointments the medical team will need to know certain pieces of information to assess your healing. Your care team can help to log and monitor things like your pain level, food and fluid intake, medications taken, and any bruising, swelling or redness.

13. Exercises: Post-procedure recommendations may include some type of therapy or exercises. A member of your care team can assist with consistent completion of exercises to enhance your recovery.

14. Bill pay: Prolonged physical or cognitive impairment from procedures and some treatment may mean you will need assistance with paying bills. You may be able to set up automatic payments through your bank but if this is not your preference or not an option, ask a trusted member of your care team to help.

Depending on your procedure and anticipated recovery, your needs may be different or more specific than what is listed here. The specialist's office will have a nurse, physician's assistant or social worker who can give you details

HOSPITAL VISITATION RIGHTS

Federal regulations enacted in 2011 require any hospital that accepts Medicare or Medicaid to take certain steps that safeguard each patient's rights with regard to visitation. Prior to that it was typical for only legal family members to be allowed to visit—now YOU get to choose who visits you in the hospital. Unless there are medical restrictions in place, the hospital is required to allow any visitors you designate, “including, but not limited to, a spouse, a domestic partner (including a same-sex domestic partner), another family member, or a friend.” Hospitals cannot limit visitation privileges on the basis of sexual orientation, gender identity, or other characteristics such as race, religion, disability, etc. You also have the right to deny visitation from anyone you choose, if there are people you do not want to see while you are in the hospital.

While nearly all hospitals in the U.S. are subject to these regulations, enforcement can vary from place to place. Ask to see your hospital's visitation policy in advance. If you're concerned about your visitation rights being honored, keep a copy of the policy with you and consider completing a Hospital Visitation Authorization Form in advance of your procedure. Note that this type of form does not allow the person named to make medical decisions or access your medical information—see *Advance Directives* for more information on those issues.

Source: [cms.gov/Regulations-and-Guidance/Guidance/Transmittals/downloads/R75SOMA.pdf](https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/downloads/R75SOMA.pdf)



of what to expect. Be sure to reach out to this person to gather as much information as possible ahead of the procedure.

If you are having an inpatient procedure, a discharge planner or social worker will likely speak with you during your hospital stay to ensure that any care needs have been addressed. Be very honest with this person about your needs so that you can increase the chances of having services put in place that are covered by insurance. It is better to set up too much care than too little, and it will be much more difficult to get additional services after you've been discharged.

Regardless of where you will recover, plan to have care team members with you as much as possible for the first 24 hours following the procedure. Anesthesia, pain and other factors may impair your functioning immediately following the procedure. Knowing there is someone available for any safety, personal care, communication or unexpected tasks that arise will provide peace of mind, and will help with staying on top of medical instructions. In some cases, having a care plan in place and people available to stay with you will make it possible for you to be discharged sooner.

Even if you remain in the hospital following the procedure, having a care team member with you to help communicate with the doctors, take notes, and advocate for you will enable you to rest and focus on healing. Specialists tend to come by at sporadic times, and may speak very quickly—if you

are sleepy or woozy from medication, it may be difficult to understand what they say, so having someone there to handle those communications can be important. Your care team member can also keep track of which medications you've had and when, what you are allowed to eat, and other details that may be difficult to remember. They can advocate for you if you want to speak to the doctor, feel you need more medication, or otherwise aren't getting your needs met.

If your rehabilitation and recovery is taking place in a facility, it will likely be a skilled care facility with nurses and other staff available around the clock. These people will change shifts two or three times per day and it will take a few days for them to get to know you and the extent of your needs. If a care team member is available to be with you in the facility for the first 24 hours, that will help the staff orient to your needs and help you orient to the new location. Having a care team member there to advocate for you can also help to get your needs met more quickly.

Build a Schedule

Part of identifying needs is identifying *when* you will need support. Build a tentative schedule so you can speak confidently with people about what you need and when. A timeline is very helpful for people to “plug in” easily to your care plan. See the ***Comprehensive Care Plan*** worksheet on pages 26–32 for additional details.

Your medical team can share recommendations for how long you should plan to have support. The more complex the procedure, the longer you will likely need someone with you. It is better to have more care and be able to send people home than to not have help when you are not feeling well.

You may be operating at less than your usual capacity leading up to the procedure date. Notes or documentation on a calendar are good ways to stay organized while developing your care plan. Keeping detailed notes will also help you feel more in control and at the helm of the process. If the task of putting together the care plan seems overwhelming, consider asking a member of your potential care team to help you with it.

Identify Your Care Team

Step 2 in developing your care plan is identifying and confirming your care team. For many, this is the most difficult part. Many people shy away from asking for the help they need, not wanting to be a burden or preferring to think they can

handle their recovery on their own. This approach can undermine a successful surgery and healing process.

Some asks will be easier than others. For instance, you may feel much more comfortable asking a friend to make a meal than help you with a shower. Your team may be made up entirely of friends and family, or you may consider supplementing with professional service providers.

As we age or deal with illness, it can be common to isolate ourselves, and so our networks may not be as robust as they once were. In fact, LGBT older adults report that isolation is a major concern in their daily lives.³ Building your care team is one way to strengthen and sustain relationships with friends and supporters. Inviting others to have a place in your care, whether as an advocate, driver or pet sitter, can decrease feelings of loneliness at a critical time.

A closer look at your informal network can yield support from unexpected sources. Start with the people you are

³ williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Aging-A-Review.pdf

A LEGACY OF CARING

The early part of the AIDS epidemic in the 1980s found members of the LGBT community stepping up to care for friends, loved ones and even strangers who needed care and support but had no one to rely on. This legacy of caregiving has uniquely prepared LGBT older adults to care for one another as they age. When someone needs assistance, the community is often able and willing to rally around them to provide it.



closest to, your family of choice. Support within your networks may also come from friends, co-workers, neighbors, and community members. If you have been involved with a volunteer organization, spiritual group, gym, senior center, book club etc. and made connections, consider reaching out to those people. You may be surprised how eager people are to show up and help out. Finally, local LGBT community centers or advocacy organizations may be able to help find volunteers to be a part of your care team.

Realize that in the same way you want to help the people you care about, they probably want to do the same for you. Everyone needs help at one point or another, and including people in this process can bring you closer together.



want to do the same for you. Everyone needs help at one point or another, and including people in this process can actually bring you closer to them.

You may rely on your family of choice for many things, but these people may not always know their place in your care, and so making a point to clearly request their involvement is very important. When a procedure or illness is on the horizon, members of your family of choice may be concerned about overstepping their bounds. They may be ready to show up, but not know for sure whether you would welcome their involvement.

Make the Ask

Once you have made a list of people within your informal network who could be of assistance, it is time to approach them about your care needs. Think strategically about what tasks will need to be accomplished, and who in your network is capable and willing.

To make it easier, follow these steps:

1. Explain your situation and needs
2. Express why you would like them involved in your care
3. Ask if they are available and what they would like to help with
4. Encourage them to take time to think about it, and tell them that if they aren't able to help you understand

People are most successful and engaged when they have specific responsibilities that match their skill set. If you have a

Overcome Hesitation

It is likely that you will need to overcome your own hesitation in asking for support. Consider your options and anticipate how you will feel going through the procedure alone, as opposed to having people you trust at your side. Remember the times you have shown up and participated in the care of a loved one. Realize that in the same way you want to help the people you care about, they probably

friend who is a pet lover, asking them to walk the dog is a natural fit. Some people love to go grocery shopping and run errands; others may prefer to sit home and keep you company. If you have a friend who has worked as a nurse, health aide, etc. they may be best suited to helping you in the hospital or assisting with personal care. If you have someone coming from out of town to help, it is generally best for them to be there immediately before, during, and after the procedure.

SAYING THANK YOU



Here are some ideas to express your appreciation for someone's participation in your care plan. It is your personal choice to make these types of efforts; members of your care team are unlikely to be expecting it.

- Make them a favorite meal or treat**
- Give them a ride**
- Care for their pet or house when they go out of town**
- Send a small gift, such as a plant or book**
- Send a note—don't forget that a simple thank you note can go a long way**

Your relationship to each person is important as well. If you want to have specific people visit during your recovery, it serves you to let them know. If there are people you would rather not spend a lot of time with while you're recovering, you can ask them to help with tasks that involve less interaction. Your healing will proceed most smoothly when you are around the people who you find pleasant and helpful.

Remember to document the various people who are involved in your care along with their roles and contact information. This will contribute to a sense of cooperation and ensure that nothing slips through the cracks. Use the list on pages 12–14 to identify areas where people can volunteer or contribute.

It's always better to have too much care coverage rather than too little. It is easier to cancel someone than to get help on short notice. Try to plan ahead and schedule care for times when you will need the most support. For example, if you wake up at 10am every morning, bathe, take medications, get dressed, prepare breakfast, and exercise, schedule someone to be with you for that 2–3 hour period every day.

You may feel more comfortable asking if you can do something in return. This is not a requirement for asking for help, but it may be something you want to offer for your own peace of mind. See the box at left for some ideas. If you are willing to participate in someone's care in the future, make that known as well.



The Area Agencies on Aging provide services to help adults age 60+ age at home. Some of these services include health classes, computer classes, benefits assistance, case management, meals at local centers, home delivered meals for persons that are unable to leave their home (also called Meals on Wheels), caregiver assistance programs, transportation, legal services, and much more.

The Area Agencies on Aging are your one-stop shop for benefits assistance and resources. Formed in 1965, the Area Agencies on Aging are your local experts on resources and services. Participants experience a decrease in social isolation and an increase in quality of life. Call your local Area Agency on Aging to find out more.

ANNELIESE STOEVER, MSW

COMMUNITY PROGRAMS MANAGER, ST. LOUIS AREA AGENCY ON AGING, ST. LOUIS, MO

If you have a limited support system, you may be asking 1 or 2 people to spend a lot of time or energy. Prioritize your needs and secure care team members for the most important things first. If you are not able to meet all of your needs, consider engaging professional services to fill the gaps.

Professional service providers can have a significant impact on your experience during the procedure and afterwards.

Some of the services you might be eligible for include:

- Skilled Nursing Facility*
- Home Health*
- Palliative Care*
- Physical, Occupational, and Speech Therapists*
- LGBT advocates within the hospital system
- Services through the Department of Veterans Affairs (VA)

**Typically covered by insurance benefits*

Your surgeon may recommend professional services but is often limited by liability from making a specific referral. The discharge planner at the hospital or your specialist's office typically will provide you with lists of resources to investigate, then can coordinate details once you have chosen a provider.

Professional Services

In many cases, your informal network will only be part of the solution and one or more professional service providers will be brought in as well. Some services will be free or covered by insurance benefits, while others may come at a cost.

To find your local Area Agency on Aging, contact the ElderCare Locator National Call Center at 800-677-1116 or eldercare.gov.



CHOOSING THE RIGHT SERVICE PROVIDER FOR YOU



Planning ahead for your procedure offers the opportunity to identify the best professional service providers for you. These steps will help you to do that:

- Ask friends and family about their experiences and recommendations.**
- Research the highest rated providers in your area.**
- Identify your priorities and ask whether providers can accommodate them. For example, you may want help with laundry or cooking but some providers may not assist with those tasks.**
- Contact and compare 2–3 providers. Some considerations may include price, scope of services, how long the provider has been in business, hiring practices, licensing status, and professionalism.**
- Find out whether they are LGBT-friendly. Do they screen for cultural competency or provide any specific training to their staff? How have they worked with this community in the past? (Read more about finding LGBT-affirming providers on page 10.)**

If you know you are likely to need certain services, it may be helpful to research them in advance. You'll find some tips for choosing service providers to the left and on the next page. It is best to have two or three choices prepared in case a service is unavailable or a facility is full.

There may be other free or discounted services available in your area to supplement care. Your local Area Agency on Aging can refer you to services such as home delivered meals, transportation, case management, minor home repair, and benefits review. Your insurance company, health care provider or local LGBT center may also have care coordinators in place to help.

Hiring a Professional Service Provider

One advantage to hiring professional service providers is their experience. Where your informal network can supply general care, professional service providers are specialists. Their knowledge of medical systems, rehabilitation and recovery can significantly improve your recovery and help you to avoid setbacks. Some of the providers you could hire to help manage your care include:

- Private Duty Caregivers
- Care Manager
- Meal Delivery
- Cleaning Service



We are especially grateful and indebted to the current generation of LGBT older adults. Many are the unsung heroes who paved the way for the advances in civil rights we enjoy today.

The trainings offered by SAGE have been invaluable in ensuring cultural competency among both care partners and administrators. For us to live these values, it's vital that they are shared by employees at all levels of our organization."

JOE FISHER, MBA

DIRECTOR OF CLIENT SERVICES, RENEWAL CARE, CHICAGO & NEW YORK

CHOOSING QUALITY SERVICE PROVIDERS



Check with your State Department on Aging or eldercare.gov:

- Is the provider properly licensed in your state?

- What overall ratings has the provider received?

- Are there any complaints registered against the provider?

Additional items to consider:

- Does the provider accept your insurance?

- For rehabilitation facilities, are they close to home/accessible for friends to visit?

- Is the provider LGBT-affirming? (see page 10 for more information)

When identifying whether a care task is best completed by a member of your informal network or a professional service provider, consider these three questions:

1. Does the task require specific training?
2. How much time will it take?
3. What will be the impact to your health if something goes awry?

For example, if you require wound care, there may be a wound care nurse who will come to clean and dress the wound a few days each week. That person is trained to monitor the critical aspects of your healing and is part of a system of professional services at your disposal. If you are having an outpatient procedure and you will need someone to pick up prescriptions or groceries and walk your dog, those tasks can be completed by someone in your informal network.

Special Topic: Advance Directives

Advance directives are a set of legal documents that provide detailed instruction on your wishes. Procedures and surgeries provide an opportunity to consider putting some of these important documents in place, and some institutions will even require it.

Advance directives are fundamentally about empowering you to manage your care and property throughout life. They allow you to make your wishes clear in case you are unable to communicate them. Without advance directives, medical decisions may be left to the medical team or to your legal “next of kin,” which means your parent or sibling might be given decision-making power rather than your best friend or partner. Lack of direction can cause discord within your care team, or result in medical decisions being made that you would not have wanted. Clear advance guidance ensures that your wishes are respected, and also empowers your decision-makers to feel confident about the choices they make.

The most commonly needed advance directives include the following:

- **Medical Power of Attorney** (sometimes called a **Health Care Proxy**) — Designates someone to make medical decisions on your behalf, generally while you are under anesthesia or if you become unable to communicate. See the next page for a

discussion on choosing your power of attorney.

- **Living Will** or **5 Wishes document** — Records your own wishes for medical care, such as which methods of life-sustaining treatment you would want if they were needed. This document can be used in conjunction with a power of attorney to guide decision-making, or can stand alone
- **Hospital Visitation Authorization Form** — Dictates who you do and/or do not want to visit you in the hospital. See the discussion on page 14.
- **HIPAA Waiver** — Allows someone to access your medical information, and enables doctors to speak with them in detail about your care.
- **Financial Power of Attorney** — Enables someone to make financial transactions on your behalf. This can be set up to take effect only if you are incapacitated. It is strongly recommended that you seek legal assistance before completing this document.
- **Will** (sometimes called **Last Will and Testament**) — Dictates how your assets should be distributed upon your death. It is recommended that you consult a lawyer for help writing a will but you can create a simple one for free at willing.com.

- **Other documents**

Documents can be written up to indicate other aspects of your wishes, both during your care and in the event of your death. You might draft a personal statement indicating how you wish to be identified (chosen name, pronouns, etc.). You might also choose to pre-arrange your funeral, pre-write your obituary, specify how you want your remains handled, or designate someone to do these things on your behalf. Lambda Legal's *Take the Power* toolkit (lambdalegal.org/takethepower) explores some of these options in more detail

CHOOSING YOUR POWER OF ATTORNEY

Many hospitals will require a Power of Attorney for Health Care (POA) form to be signed and submitted prior to the procedure, in case decisions need to be made while you are under anesthesia. The person designated as your POA is your trusted representative who understands your wishes and can interact with medical staff to make decisions on your behalf. Note that providing an emergency contact or naming your caregiver per the CARE Act (see page 8) is not the same thing as designating someone as your POA.

The person you choose as your POA should be trustworthy, knowledgeable about your wishes and medical history, and committed to your long term well-being. This person might be a spouse, partner, child, family member or close

friend. Be certain to take some time to carefully consider who in your life is best suited for this critical role. It is important to communicate with the people you've identified as your POA and successor POA so they are aware and agree to the responsibility. They should have copies of the documentation for when the need arises, and your doctor and/or hospital should have copies in their files as well.

ADDITIONAL RESOURCES

Advance directive forms vary from state to state and may require signatures from a doctor, notary public, attorney or other witnesses. State-specific forms and instructions can be obtained from your state health department or local Area Agency on Aging, or at the following websites:

- **AARP:** aarp.org/advancedirectives
- **National Hospice and Palliative Care Organization:** caringinfo.org/advancedirectives
- **National Healthcare Decisions Day:** nhdd.org/state-specific-resources
- **Five Wishes:** agingwithdignity.org

See the *End of Life Decisions* section of the National Resource Center on LGBT Aging (lgbtagingcenter.org) for additional resources on advance directives.





CONCLUSION



Putting Your Plan Into Action

IMPLEMENTATION

This third step brings all the tasks, care team members and medical details together in one central location. In creating a care plan, you have drafted a document to keep your team connected and yourself organized. As you approach your procedure, it is time to put your care plan into action.

DOCUMENTATION

Documenting your condition, needs, care team members, etc. can save you time and energy. Explaining your condition over and over, connecting with friends and family, and coordinating details can be draining. A care plan can function as an informational document for your medical and care teams and as a reference document for you.

There is no one way to create a care plan, so make something that fits your needs. The worksheets included in this guide are meant to serve as examples and tools. If the format doesn't make sense to you, other options might be to use a notebook, a computer program or a notetaking app. The information should be in one place and easily accessible to care team members.

COORDINATION

Communication with the care team, medical providers and other parties is very important. Focus on being clear and concise with all communications. Check in with your care team in the weeks and days prior to the procedure, and ensure that everyone is clear on their roles and that any questions have been answered. Review your plan as well to make adjustments and updates if necessary. It is a good idea to call everyone the day before the procedure to reconfirm. This type of coordination is something a care team member can do for you if you have enough support.

It's hard to know how you will feel after a procedure, so it is a good idea to have a member of your care team identified to act on your behalf if needed. This person may be your POA or another trusted individual. They should be prepared to step in and coordinate the team if you aren't feeling up to it. This point person is also a resource to address and solve any issues that arise unexpectedly.

The medical team needs to be informed that you have a care team and a plan for after your procedure. They may ask for the contact information of the POA and the people caring for you in the



As you prepare to interface with your local healthcare system, keep in mind that most physicians, physician’s assistants, nurse practitioners, floor nurses, diagnostic techs and nurse’s aides are clueless about who you may actually be. Many have limited or no frame of reference for understanding you as a person. What they see upon making your acquaintance is a big mystery! Some will be motivated by curiosity and ask probing questions in an effort to understand. Obviously, this is not always helpful to you. Others may simply be so anxious about taking care of someone different from him or herself that they will do the minimum and then high-tail it on to the next case. This is never helpful.

So, what can you do to orchestrate better outcomes for yourself or your loved one? Plan ahead! Plan ahead for dealing with the sometimes clueless and anxious person assigned to help you. Be prepared. Draft a short self-declaration statement about who you are and include in it specific guidelines about your preferred gender identification, how you prefer to be addressed, who you want included in your care and your goals for treatment. This is information that will make sense to your caregivers. In most cases, one or several individuals on your health care team will actually get it, and they will model a respectful approach to your care and hold their peers accountable to do the same!

Your self-declaration statement does not have to be complicated. Keep it short, simple and detailed. And write it before you need it. Have it on hand. Consider it your ‘Power of Preparation’ Form. Ask that it be placed in your chart for all to read. Approaching ignorance with information works every time. At first glance, this strategy may seem like enabling the establishment not to teach themselves, but in the end it will improve your healthcare outcomes. Something to consider including in your Care Plan!”

D.J. POPOVICH MA, RN

NURSE NAVIGATOR, PRESENCE HEALTH, CHICAGO

days after returning home. It is important for your care team to have the medical providers’ contact information as well. These details will be critical if there are complications or questions, or if general follow-up communication is needed.



CONGRATULATIONS!

By taking the initiative to make a care plan, you have prioritized your health and recovery. Facing a procedure and the changing needs that come with it can feel overwhelming. In identifying your needs, building a care team, and documenting a care plan, you have taken important steps to be in control of your health.

Comprehensive Care Plan

PROCEDURE DETAILS	
NAME	TYPE OF PROCEDURE(S)
DATE OF BIRTH	SURGEON
POA <i>Health</i> <i>Finance</i>	HOSPITAL <i>Ph#/Address</i> <i>Length of Stay</i>
INSURANCE	REHAB LOCATION
CO-PAY	REHAB DATES
ADVANCE DIRECTIVES <input type="checkbox"/> POA for health <input type="checkbox"/> POA for finance <input type="checkbox"/> Living Will <input type="checkbox"/> Other	POST SURGERY MEDICATIONS <i>Pain</i> <i>Antibiotic</i>
HOME HEALTH	FOLLOW-UP APPOINTMENT
OTHER SERVICES	EXPECTED RETURN TO NORMAL ACTIVITY



Comprehensive Care Plan *continued*

MEDICAL

ALLERGIES

MEDICAL HISTORY

MEDICATION LIST

SUPPLIES / MATERIALS

MEDICAL

- Wheelchair
- Cane
- Commode
- Urinal
- Incontinence Products
- Other:

FOOD

Grocery List:

MISCELLANEOUS



Comprehensive Care Plan *continued*

STEP 1 - IDENTIFY NEEDS

	ADVOCACY	EQUIPMENT	TRANSPORT	HOUSE-KEEPING	PET CARE	PERSONAL CARE	MEDICATION
PRE-PROCEDURE							
DAY OF PROCEDURE							
POST-PROCEDURE							
WEEK 1							
WEEK 2							
WEEK 3							
ONGOING							

	COMMUNICATION	MONITOR HEALTH	GROCERIES/ MEAL PREP	WOUND CARE	COMPANY	OTHER
PRE-PROCEDURE						
DAY OF PROCEDURE						
POST-PROCEDURE						
WEEK 1						
WEEK 2						
WEEK 3						
ONGOING						



Comprehensive Care Plan *continued*

CARE CALENDAR #2				
	APPOINTMENTS	SHIFT	WHO	OTHER NOTES
MON				
TUES				
WED				
THURS				
FRI				
SAT				
SUN				
<hr/>				
MON				
TUES				
WED				
THURS				
FRI				
SAT				
SUN				

Simplified Care Plan *continued*

PROCEDURE DETAILS	
NAME	TYPE OF PROCEDURE(S)
DATE OF BIRTH	SURGEON
POA <i>Health</i> <i>Finance</i>	HOSPITAL <i>Ph#/Address</i> <i>Length of Stay</i>
INSURANCE	REHAB LOCATION
CO-PAY	REHAB DATES
ADVANCE DIRECTIVES <input type="checkbox"/> POA for health <input type="checkbox"/> POA for finance <input type="checkbox"/> Living Will <input type="checkbox"/> Other:	POST SURGERY MEDICATIONS <i>Pain</i> <i>Antibiotic</i>
HOME HEALTH	FOLLOW-UP APPOINTMENT
OTHER SERVICES	EXPECTED RETURN TO NORMAL ACTIVITY

MEDICAL
ALLERGIES
MEDICAL HISTORY
MEDICATION LIST



Simplified Care Plan *continued*

CONSIDERATIONS

Remember to keep in mind the various tasks you may require support to complete safely. Think about including transportation, meal preparation, medication pick-up and reminders, personal care tasks, pet care, companionship and other areas outlined in the guide.

WHAT DO I NEED?	WHEN	WHO (Name/contact information)	DETAILS
Pre-procedure			
Day of procedure			
Post-procedure			
Week 1			
Week 2			



Glossary

Advance Directives: Set of legal documents which identify decision-makers for health and financial considerations. Advance directives can include a Living Will, Power of Attorney, and DNR forms. These documents direct family, friends and medical staff about a person's end-of-life wishes if they lack the ability to make or communicate decisions.

Area Agency on Aging (AAA): Local agencies created under the Older Americans Act to oversee and manage a wide variety of programs and services for older adults.

Care Team: The friends, family and acquaintances who actively participate in the care of an individual. Often the care team coordinates to address post-procedure needs such as meal preparation, medication reminders, housekeeping, transportation, and companionship.

Discharge Planner: Typically a social worker or nurse case manager who coordinates discharge from the hospital. Responsible for providing care options and setting up a plan for post-procedure support.

DNR (Do Not Resuscitate order): Provides instruction on cardiopulmonary resuscitation and life support in case of emergency. Utilized frequently in hospital or long term care settings to ensure a patient's wishes are clarified and respected.

Family of Choice: Diverse family structures and support networks that include but are not limited to life partners, close friends, and other loved ones not biologically related or legally recognized but who are the source of social, emotional and caregiving support.

Geriatric Care Manager: A health and human services specialist who acts as a guide and advocate for families who are caring for older relatives or disabled adults. They are educated and experienced in any of several fields including nursing, gerontology, social work, or psychology, with a specialized focus on issues related to aging and elder care.

Gender Affirming Surgery: Surgical procedures that change one's body to conform to one's gender identity. Sometimes referred to as "gender reassignment surgery" or "gender confirming surgery."

HIPAA: Health Insurance Portability and Accountability Act which protects medical records and health information.

Home Health: Short-term health care services that can be provided in a patient's home for recovery from a procedure, illness or injury.

Hospice: Medical care provided in a person's home or an inpatient unit to provide comfort during the end-of-life process.

Inpatient: Medical care that requires formal admission to a hospital. For inpatient surgical procedures, you will stay in the hospital overnight after the procedure, and possibly longer.

Outpatient: Medical care that does not require hospital admission. For outpatient surgical procedures, you will leave the hospital (or specialist's office) the same day.

Palliative Care: Specialized medical care for people with chronic or serious illnesses. The approach focuses on symptom management and comfort.

Physician's Assistant: A nationally certified and state-licensed medical professional who works within healthcare teams.

Primary Care Physician (PCP): The medical professional at the center of a person's care. A PCP is knowledgeable about many common health conditions and can provide advice and referrals when necessary. Typically a doctor, but could also be a nurse practitioner.

Rehabilitation Center:

A licensed healthcare residence that provides continued care for those who are medically stable but still need significant assistance, and offers various therapies aimed at restoring functional ability and quality of life.

Residents/Fellows:

Doctors who have completed medical school, and are gaining additional skills in a specialized field. Often a resident or fellow will interact with you directly, and report back to the specialist.

Specialist: Doctor who has extensively studied a particular area of medicine. In this guide ‘specialist’ may refer to a surgeon or the professional completing the planned procedure.

Vital Signs: Measurement of a person’s temperature, pulse, blood pressure and respiratory rate. Indicates proper and improper body system functioning.

Additional Resources

SAGE

The country’s largest and oldest organization dedicated to improving the lives of LGBT older adults through advocacy and direct services sageusa.org

National Resource Center on LGBT Aging

Resources and education for providers, LGBT older adults and caregivers. lgbtagingcenter.org

Free Care Calendars and Communication Tools

carecalendar.org
lotsahelpinghands.com
caringbridge.org
mealtrain.com

Gender Affirming Surgery

Trans 101 for Trans People
openmindedhealth.com/transgender-101-trans-people

A Guide to Our Services for Transgender, Genderqueer and Gender Expansive Clients

whitman-walker.org/wp-content/uploads/2015/02/TransgenderResourceGuide_Web.pdf

SAGE LGBT Elder Hotline

Peer support, information and local resources. [1-888-234-SAGE](tel:1-888-234-SAGE)
sageusa.org/hotline

SAGECare

Cultural competency training and consulting on LGBT aging issues for service providers, and a searchable database of providers who have earned a SAGECare credential. sageusa.care

Finding LGBT-Affirming Providers

hrc.org/hei
GLMA.org
WPATH.org
radremedy.org
sageusa.care/sagecare-providers

Advance Directives

lambdalegal.org/takethepower
aarp.org/advancedirectives
caringinfo.org/advancedirectives
nhdd.org/state-specific-resources
willing.com
agingwithdignity.org



Find this guide online and download copies of the worksheets at lgbtagingcenter.org/careplanning



Advocacy &
Services for
LGBT Elders

We refuse to be invisible

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