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## SELF-MANAGEMENT OF CARE

### INTRODUCTION

Self-care centers an individual's ability to preserve and/or improve their mental and physical health through routine lifestyle choices. The general public might consider self-care to be taking time out of one's day to exercise, journal, go to sleep early, or maintain a relationship with a mental or clinical health care provider. Although self-care can include these practices, self-care is much broader than practicing healthy habits, and embodies taking care of all aspects of one's health and well-being. This primer explores the complexity of self-care, specifically, the self-management of care and its role in harm reduction, and increased access to health care resources and information. The self-management of care is about the fundamental right to bodily autonomy and includes the ability to make choices about a person's own body.

A tenet of upholding and honoring the right to bodily autonomy is protecting people's ability to make informed decisions related to health care, including what care they receive, when and how they receive care. The ability to self-manage one's own care is an integral and critical part of supporting individual agency and autonomy related to health care decision making. This primer provides an overview of self-managed of care, including why people self-manage, self-management as an expression of bodily autonomy, and an introduction to some of the key types of care people often seek to self-manage: abortion, contraception, gender affirming care, and HIV treatment and prevention.

### WHAT IS SELF-MANAGEMENT OF CARE?

[Self-management of care](#), also known as self-managed care or self-care, refers to a spectrum of care that can be provided fully or partially outside the formal health care systems and can be used with or without a health care provider.

The World Health Organization [WHO] defines [self-care](#) as "the ability of individuals, families and communities to promote health, prevent disease, maintain health, and cope with illness and disability with or without the support of a healthcare provider." The [WHO's](#) definition of self-care focuses on recognizing people as active agents in the management of their own health care, particularly when it comes to health promotion, disease prevention, self-medication, rehabilitation, and palliative care. Self-care is

strongly influenced by [evidence-based interventions](#), including medications, counseling, diagnostics, and/or digital technologies that can be accessed and used either fully or partially outside of traditional health care settings. The WHO recognizes that self-care and self-care interventions can [empower individuals](#) and communities to manage their own health and well-being in alignment with their preferences, cultural practices, and individual circumstances.

Self-management of sexual and reproductive health care refers to people's ability to self-manage aspects of their sexual and reproductive health, including contraception and family planning, sexually transmitted infection (STI) prevention, testing, and treatment, the full spectrum of gender-affirming care, and other forms of preventive reproductive health care. This primer focuses on four key types of self-managed sexual and reproductive health care: abortion care, gender-affirming care, contraceptive care, and HIV prevention.

As people face numerous barriers to health care including reproductive health care deserts, increased restrictions and bans on abortion and gender-affirming care, discrimination, and rising costs of care, there has been growing awareness and acceptance of self-managing one's own care. However, it is important to recognize that a lot of people do not choose to self-manage simply to avoid the barriers to formal systems of care. Rather, for some, self-management is often sought out because it is the best choice for the person's situation, personal preferences, goals, values, and so much more. Access to the full spectrum of sexual and reproductive health care, including self-managed care, is crucial for preserving the right to bodily autonomy and ensuring reproductive freedom for all.

### ***Self-managed care and the right to bodily autonomy.***

Self-managed care can be a way of expressing someone's right to bodily autonomy, when people who self-manage make the decision to do so because it is what is best for their circumstances, needs, desires, and, ultimately, their lives. Both [Reproductive Justice](#) and [liberatory harm reduction](#), two central philosophies and frameworks dedicated to uplifting the human right to bodily autonomy, call for the importance of preserving one's ability to self-manage their own care.

The ability to access care in the way you feel is best is a key tenant of Reproductive Justice. *Sistersong* defines [Reproductive Justice](#) as "the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities." The [Reproductive Justice](#) framework maintains that every person has the right to have access to the full spectrum of sexual and reproductive health care, including abortion care, contraceptive care, pregnancy and maternal health care, STI care, and gender-affirming care. The right to maintain personal bodily autonomy includes the right to decide what type of health care a person receives, how they receive that care, and when they receive care, all of which must include respecting a person's decision to self-manage their care should they

desire and ensuring people are able to self-manage without barriers or restrictions, and most importantly, without the risk of criminalization.

The ability to self-manage care without barriers is also crucial for liberatory harm reduction. Like Reproductive Justice, [liberatory harm reduction](#) is rooted in true-self-determination and total bodily autonomy. The core of the [harm reduction philosophy](#) is about trusting that an individual is the best person to make decisions about their own health, well-being, and lives. Harm reduction focuses on supporting people as they determine what is best for themselves and act on these decisions by accessing care on their own terms. Liberatory harm reduction focuses on disentangling and disconnecting the formal medical system from carceral thinking and systems, and ensuring people are in control of their choices without risk of incarceration. Although harm reduction is most commonly and frequently associated with substance use and sex work, these underlying principles and philosophies are at the heart of all forms self-managed care. Being able to manage one's own care, no matter the type of care, is crucial to upholding bodily autonomy, Reproductive Justice, and liberatory harm reduction.

**There is no single definition of what “self-managed care” is**, as self-managing one's care can and will look different for every person, as the care is informed by their life circumstances, their preferences and needs, and a host of more decisions. Ultimately, “self-managed care” encapsulates a spectrum of forms of care, the role and level of involvement that the formal medical system takes in the self-care, and the reasons people choose to self-manage their care. The key take-away is no matter the reason or how a person decides to self-manage their care, they should have access to non-judgmental and affirming support as they navigate their care.

### **SELF-MANAGED ABORTION CARE.**

Self-managed abortion care is commonly described as receiving abortion care in part or entirely outside of a formal, clinical setting. Self-managed abortion care with medication often uses mifepristone and/or misoprostol, the FDA approved abortion pills. As abortion bans and restrictions increase, the use of medication abortion has increased. Although mifepristone and misoprostol are usually taken [together](#), many individuals seeking to self-manage their abortions can also use the [misoprostol only regimen](#). The use of misoprostol alone has been used for [decades](#) and is another [safe and effective way](#) to terminate a pregnancy. The ability to self-manage an abortion can support individuals to maintain control over their reproductive health and lives. As stated above, there are many reasons that people may choose to self-manage their own abortion, regardless of the status of abortion restrictions in their state.

Self-managed abortion is not a new phenomenon. Throughout history, people have controlled their fertility and managed undesired or mistimed pregnancies through various means, including the use of herbs and physical techniques, such as abortion massages. Herbal abortions involve the use of plants and other natural remedies to induce abortion, and when used correctly, can be a safe and effective method of self-managed care. Today, many people still choose this path because it aligns with their

values and cultural practices or because it is the most accessible option for them. Ensuring people have the resources and information they need to pursue safe herbal abortion methods is essential in supporting reproductive freedom and bodily autonomy.

People can also receive support for self-managed abortion care through telehealth, services that use technology to provide health care from a distance, and abortion services that provide medication abortion via mail. Telehealth plays a major role in self-managed abortion care by providing people with the means to receive mifepristone and misoprostol or other forms of medication to terminate a pregnancy. Virtual services for self-managed abortion care alleviate many barriers for individuals living in rural communities, those without access to abortion services in their own community requiring that they travel long distances for care, and those who live in states with abortion restrictions and outright bans. Medication abortion via telehealth is a safe and effective method that is preferred by many people seeking abortion. It provides the opportunity for people to manage their own care with minor support from the formal health care setting that meets their needs for safety, privacy, and comfort.

Self-managed abortion care, whether completed through medication or herbal methods, offers benefits in terms of privacy and autonomy and can be safe and effective when individuals have access to accurate information, support, and resources. The biggest risk that individuals self-managing their care face is not physical or medical, but instead the risk of criminalization due to the legal and social landscape of the U.S. that seeks to punish those seeking this form of care. This care is particularly important for individuals who are already impacted by other forms of oppression and marginalization or who have been historically mistreated by the medical system, including people of color, people in rural communities, people experiencing poverty, young people, and LGBTQIA+ people.

The practice of self-managed abortion care, whether through medication, herbal methods, or other means, is a critical pillar of Reproductive Justice that emphasizes autonomy, empowerment, and self-determination. While this care is vital, it is also important that people are not forced to self-manage if it is not the form of abortion care that they want. As abortion access continues to face attacks on the state level, it is vital to ensure that people have access to options for self-managing their care. Each person deserves access to accurate information, resources, non-judgmental support, and legal protections to make the choices that are best for their bodies and lives.

### **SELF-MANAGED GENDER-AFFIRMING CARE.**

Gender-affirming care is essential health care that supports transgender and gender-expansive people in aligning their bodies (the physical) with their gender identity (the social and societal). Like abortion, this care is lifesaving and supports individuals in making important decisions about their lives and well-being. [Historically](#), transgender and gender-expansive people have always existed and always found ways to manage their own care, often outside a formal medical system that has ignored, neglected, or mistreated them. Self-management can reflect resilience, autonomy, and authenticity,

but it also reveals gaps in health care access for the most vulnerable members of our community.

Today, it is still very common for transgender individuals to manage their gender-affirming care independently due to [barriers in the medical system, such as stigma, high costs, and a lack of knowledgeable providers](#). In these cases, people may rely on community support, accessing hormone replacement therapy through peers or online sources (like the [DIY HRT Directory](#)), and using non-medical means to affirm their gender. Practices such as [binding, packing, tucking](#), and [socially changing names and pronouns](#) are common ways transgender and gender-expansive people take control of their gender expression, often without the help of medical professionals. Even with the help of medical professionals and through medical means, queer and transgender people are caring for themselves when they administer hormones through injections, gels, and oral medications.

Despite increased transgender and queer visibility, the current sociopolitical landscape still lacks the respect, compassion, and understanding that many transgender and gender-expansive people deserve. Although this is the result of multiple contributing factors, the uptick in anti-trans legislation ([over 650 anti-trans bills introduced since the start of 2024](#)) has reshaped what limited access queer and trans people have in order to receive the care they need. Queer and trans people need access to gender-affirming care not only to live as their authentic selves, but also for survival in the wake of increased levels of discriminatory violence. As a result, for some, self-managed care is a response to an inequitable health care industry and a reflection of systems that often overlook and further marginalize transgender people. Self-managing one's own gender-affirming care can put power back into the hands of queer and transgender people, empowering them through autonomy and expression.

While empowering, it must be noted that when individuals turn to non-prescribed hormone therapies or consider "do it yourself" (DIY) surgical procedures with inexperienced or predatory providers, there is an increased level of risk. In efforts to ensure that people of transgender experience can access the safest care possible, it is important for providers to serve as advocates for the trans community. This is done by actively working to dismantle discriminatory practices in health care and being accountable for how they may perpetuate white supremacy culture that reinforces and strict gender binary, intentionally or unintentionally. This is the best way to ensure that all patients receive safe, secure, and supportive gender-affirming care.

Additionally, providers must recognize that transgender people have always managed their care and are the only experts in their own lives. Collectively, we must acknowledge this expertise rather than pathologize, criminalize, or dismiss it. Trust is foundational to the patient-provider relationship. Providers and patients should have a collaborative, inclusive relationship rather than a unilateral one.

Health care professionals have a vital role in harm reduction and the cultivation of safe spaces for transgender and gender-expansive people. Whether at physical clinic, or

through telehealth online appointments, when health care providers offer compassionate, informed, and accessible care, they help transgender people achieve and maintain fulfilling, authentic lives.

## **SELF-MANAGED CONTRACEPTIVE CARE.**

[Self-management of contraceptive care](#) refers to the ability of an individual to promote and maintain their own sexual health and to prevent, space, and plan their pregnancies, with or without the support of a provider. Contraceptive care is not often discussed in terms of self-managed care, but managing one's own family planning is commonplace. From buying condoms at the local drug store to self-injection of contraceptive injectables, there is an entire spectrum of contraceptive care that people are able to manage on their own with little to no interaction with the formal health care setting. Access to the full spectrum of contraceptive care must include the ability to self-manage contraceptive care, if that is what the person decides is best for them.

[Awareness-based contraceptive methods](#), commonly referred to as natural family planning, are forms of self-care where a person relies on tracking their own menstrual cycle, cervical mucus, and body temperature to identify which days they are most likely to get pregnant. There are two types of [cycle tracking](#) a person can rely on for awareness-based contraception: menstrual cycle awareness (MCA) and fertility awareness method (FAM) charting. [MCA](#), as the name suggests, relies on keeping track of one's menstrual cycle and noting patterns over several cycles. [FAM charting](#) relies on paying attention to different fertility biomarkers, including basal body temperature and cervical mucus, to track one's ovulation and identify "[safe days](#)" one can have sex with a decreased chance of conceiving.

Although awareness-based methods are a part of self-managed contraceptive care, they are not the only options available. People who want to self-manage can access a wide spectrum of contraceptive care with no or minimal interaction with formal health care settings if that is what they choose. For example, [barrier contraceptive methods](#) include any type of contraceptive that works by physically blocking sperm from the uterus to prevent conception. Some types of barrier contraceptives are easily accessible over the counter (OTC) at any local pharmacy, convenience store, or supermarket, including both internal and external condoms and spermicides. Additionally, in some places, barrier methods can be obtained for free from community health programs, like [condom distribution programs](#). [Cervical caps](#) and [diaphragms](#) are reusable barrier methods that are inserted into a vagina to prevent sperm from entering the uterus. These methods of birth control require at least some minimal interaction with the formal health care system as both [cervical caps](#) and [diaphragms](#) require a prescription from a health care provider to help ensure the cap or diaphragm is a proper fit for the person.

[Accessing hormonal contraceptive methods](#) often require the most interaction with the traditional health care system, as hormonal methods often require prescriptions. However, many types of hormonal methods, including contraceptive pills, patches,

rings, and emergency contraception (EC) can be accessed [fully online](#), without the need for a formal in-person physician visit. Additionally, recent wins have made it even easier for people to have access to a broader spectrum of contraceptive options for self-management. Last year, the FDA approved the first ever over the counter (OTC) [birth control pill](#). This change means that people are able to self-manage with the use of OTC [progestin-only birth control pills \(Opill\)](#). There are also growing efforts to expand access to [self-administered contraceptive injectables](#). This would allow people to self-manage with injectables without having to see a provider every few months to receive an injection.

Increased access to self-managed contraceptive care is crucial to ensure people can access the form of contraceptive method of their choice. Unfortunately, [19 million women<sup>1</sup> of reproductive age](#) live in contraceptive deserts, where they cannot access the full range of contraceptive care. Further, 1.2 women in a [county without a single health center](#) offering the full range of contraceptive care, necessitating them to rely on self-managed methods. With new wins that allow for more forms of prescription based contraceptive options to now be available OTC and via the mail, expanded access to free and low-cost barrier methods, and widely available information about awareness-based contraception, people are able to utilize a spectrum of contraceptive methods for self-management without having to rely on the formal health care system to access care.

### **SELF-MANAGED HIV PREVENTION.**

People most at risk for HIV infection have always managed their own care, especially when the formal health care system failed them. The [modern harm reduction movement](#) began during the HIV/AIDS crisis in the 1980's as a way for [community members, organizers, and people impacted by HIV](#) to support each other as they navigated HIV and AIDS, while formal care systems ignored and denied people care. Currently, [people who are most at risk for HIV infection](#) often still cannot access formal health care settings for care or seek to avoid formal care settings due to fear of discrimination, stigma, and criminalization. This is particularly true for [people who use injectable drugs](#), [people who are unhoused or housing insecure](#), and [sex workers](#). Self-management of care has always been a crucial aspect of HIV prevention, as health care systems, both historically and contemporary, have failed to provide a space where people can always get care safely and free from stigma and discrimination.

One of the most accessible and most common forms of self-managed HIV prevention is [condom use](#). Latex, polyurethane, and synthetic rubber condoms can all prevent HIV transmission and infection. As mentioned in the section about contraceptive care, condoms are a key resource for people who want to self-manage their contraceptive

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<sup>1</sup> For the purpose of the research being cited in this commentary, unless otherwise noted, “women” refers to cisgender women, as the data collected in the available research has been limited to that group. We acknowledge and understand that this is not comprehensively inclusive of all those who may use contraception, including transgender and nonbinary folks. It is essential that future research on the issue includes everyone for whom contraceptive equity is a lived concern.

care, as condoms can be easily purchased at local stores and can be obtained for free from [various community organizations](#).

Self-testing or at-home testing for HIV is also a crucial tool for HIV prevention self-management as people no longer have to rely on going to a clinic or doctor's office in order to get tested. [HIV self-testing](#) allows people to learn their HIV status on their own time and in their own space. HIV self-tests are antibody tests that can be used in any private location and can provide people with their results within 20 minutes. There are organizations like [QCare+](#) and [HealthySexual](#) that can provide people with at-home HIV tests and/or connect them with in-person HIV testing labs, depending on the individual's preferences.

[Pre-exposure prophylaxis \(PrEP\)](#) is a medication that people who are HIV negative can take to significantly decrease their risk of a HIV infection. Currently, a prescription is required for PrEP, as well as regular follow up appointments with a provider for repeat HIV tests and refills. However, there are [numerous online sites](#) that can help people access PrEP without having to go to in person appointments, significantly reducing the interactions with health care settings for people who want to self-manage their PrEP. Additionally, in nine states, Arkansas, California, Colorado, Illinois, Maine, Nevada, Oregon, Utah, and Virginia, [pharmacists](#) can prescribe PrEP, allowing people to access a prescription without having to go to a doctor's office or clinic.

Another key aspect of HIV prevention is ensuring people living with HIV have access to effective treatment, so they can achieve an undetectable viral load, significantly reducing the transmission of HIV to anyone with whom they have intercourse. This is commonly referred to as 'U=U' or 'undetectable = untransmittable'. Although people living with HIV often must rely on medical providers and the formal medical system to fully manage their care, steps have been taken to make it easier for people to access HIV medication without in-person appointments to support people who want to self-manage their HIV treatment. For example, online sites like PlushCare can connect people with online providers that can assist them with obtaining HIV and AIDS medications. Ensuring that people have support to manage their HIV treatment is crucial for a myriad of reasons, one of which is to help mitigate the spread of HIV and to ensure consistent care.

Finally, people who use injectable drugs are at a heightened risk for [HIV transmission](#) due to sharing and reusing needles, syringes, and other injection supplies. [Syringe Services Programs](#) (SSPs) and [harm reduction organizations](#) allow people to access safe use supplies, significantly minimizing their risk of HIV infections and other blood-borne disease transmissions. By being able to access harm reduction supplies, people who use drugs are able to take steps to protect their health and well-being as they see fit, without having to risk stigma, discrimination, and criminalization for their substance use by interacting with the formal health care system.

Although some of the most successful ways of preventing HIV transmission require at least some involvement with the formal health care system, there are multiple avenues people seeking to self-manage their HIV prevention to minimize interactions with formal health care settings as they see fit.



## CONCLUSION

Self-managing one's own sexual and reproductive health care is crucial to preserve the right to bodily autonomy. While managing one's own care is something everyone should have the resources and information to do, it holds even more eminence for those at the margins of care. Queer and transgender people, people living with HIV/AIDS, those experiencing poverty, and those living in rural communities should be supported and trusted to manage their own care regardless of the reason they chose to do so.

People deserve full access to the full spectrum of care, which must include support for people as they manage their care fully or partially outside the formal health care setting and protections for people to self-manage without risk of discrimination or criminalization. Contrary to popular belief, many people, queer and transgender people specifically, have always managed their own care. As clinical providers, policymakers, and advocates, we have an obligation to continue our allyship with the most vulnerable members of our community, ensuring that they are not just positioned to survive, but to thrive.

## ADDITIONAL RESOURCES ON SELF-MANAGING YOUR OWN CARE.

### *Abortion Care*

- [Abortion on Our Own Terms](#): Resources on self-managing abortion with pills and abortion care with telehealth.
- [AbortionFinder](#): Comprehensive directory of trusted and verified abortion service providers and assistance resources in the United States.
- [All-Options Talkline](#): A talk line about the full spectrum of pregnancy experiences and decisions, including abortion, miscarriage and pregnancy loss, parenting, and infertility.
- [Connect & Breathe](#): Confidential, toll-free after abortion talkline with trained staff who listen and provide unbiased support.
- [Digital Defense Fund](#): Resource guide for digital privacy recommendations and information around keeping your abortion private and secure.
- [DOPO](#): Directory of abortion doulas to support people before, during, and after their abortion.
- [Exhale Pro-Voice](#): Confidential text and talkline for nonjudgmental after-abortion support.
- [Holistic Abortions](#): Resources on holistic, herbal, and home abortion care.
- [If/When/How Repro Legal Helpline](#): Free, confidential helpline to access legal information or advice about self-managed abortion care.
- [Ineedana.com](#): Resource to provide people seeking abortion care with relevant information about how they can access care.
- [M+A Hotline](#): Confidential, private, secure phone and text hotline for self-managing abortion and miscarriage care.
- [Plan C](#): Guide for how to obtain abortion pills in every state.

- [ReproCare](#): Confidential healthline that provides peer-based, trauma-informed emotional support, medical information, and referrals to people seeking abortion care.
- [Self-Managed Abortion; Safe & Supported \[SASS\]](#): A global nonprofit organization that provides information and resources on how to use medication abortion pills, with or without a clinician.

### Gender Affirming Care

- [Folx Health](#): A health and wellness platform for the LGBTQIA+ community that provides gender affirming care, primary care, therapy and mental health care, and sexual and reproductive health care.
- [National Black Justice Collective \(NBJC\)](#): Resources for Black transgender, gender-nonconforming, and nonbinary people and communities.
- [Plume](#): A trans-led healthcare organization that provides gender-affirming hormone therapy and transition support.
- [Point of Pride](#): A resource fund that provides financial aid and direct support to trans folks in need of health and wellness care.
- [TBuddy](#): Bridges the critical gap in mental health support for transmasculine individuals by providing a 24/7 peer support network grounded in lived experience.
- [Snap4Freedom](#): An advocacy organization that strives to build safety within the Black LGBTQIA+ community, by investing in our collective embodied leadership, and building political power.
- [The DIY HRT Directory](#): A directory that provides guides and resources for people seeking to self-manage gender affirming care, including a Transmasc Guide, a Transfem Guide, information on injection supplies, and information on reliable telehealth options for GAC.
- [Trans Advocacy & Care Team \(TACT\)](#): A virtual network of peer support aimed at improving trans individuals' overall wellbeing by reducing isolation and barriers to care.
- [TrueUClinic](#): Independent medical organization that provides personalized online hormone therapy for transgender and non-binary folks.

### Contraceptive Care

- [Bedsider](#): Online birth control support network.
- [Folx Health](#): A health and wellness platform for the LGBTQIA+ community that provides a wide spectrum of care, including birth control, emergency contraception, and family planning services.
- [Nurx](#): Independent medical organization that helps people access prescriptions for contraceptive care, including emergency contraception, via the mail.
- [Opill](#): Resource for locating retailers near you where you can obtain Opill over the counter.
- [PP Direct](#): App run by Planned Parenthood that connects you to a provider to access birth control, including emergency contraception from your phone.

- [User Guide for Depo-Provera Sub-Q: The Do-It-Yourself Shot](#): Guide by Reproductive Health Access Project on how to access and use self-injectable contraceptive shots.

### **HIV and Other STI Prevention**

- [Folx Health](#): A health and wellness platform for the LGBTQIA+ community that provides a wide spectrum of care, including HIV testing, treatment, and PrEP services.
- [Gettested.cdc.gov](#): Resource that helps you find organizations in your area that offers free or reduced cost HIV, STI, and Hepatitis testing, including self-tests.
- [GoodRx](#): Provides a resource to identify free condom distribution programs for in-person pickup or delivery by mail in every state.
- [HealthySexual](#): Comprehensive guide on STI and HIV testing and prevention, including locating testing sites, information on at-home and self-testing, and accessing PrEP, PEP, and HIV treatment.
- [HIV.gov Services Locator](#): HIV services locator that can help people locate a variety of services, including PrEP, mail in HIV self-tests, rapid HIV/STI self-tests, and condoms.
- [National Harm Reduction Coalition](#): Resource to find local harm reduction resources and organizations near you.
- [Nurx](#): Independent medical organization that helps people access sexual health care resources via the mail, including common STI at-home tests, HPV at-home tests, HIV at-home tests, and PrEP prescriptions.
- [Q Care Plus](#): Independent medical organization that helps provide gender affirming HIV-prevention care, including HIV and STI at-home testing, PrEP prescriptions, and at-home medication delivery.
- [Ready, Set, PrEP](#): A program that provides free PrEP to people living in the United States who are HIV-negative and lack prescription drug coverage.