Creating End-of-Life Documents for Trans Individuals: 
An Advocate’s Guide

Discussions about end-of-life or emergency care are never easy, even for people who know with certainty what kind of care they would want to receive. Not only is it unpleasant to reflect on one’s mortality, it is also frightening to realize that in these critical situations it will be someone else – and not oneself – who is responsible for making sure one is treated appropriately.

Because people who identify as transgender or gender-nonconforming often have special healthcare needs or face unique forms of discrimination in accessing care, crafting advance healthcare planning documents is especially critical from an advocate’s perspective, not to mention from the perspective of the clients themselves. Healthcare planning documents can and should be written for trans individuals to ensure that a respectful decision-maker is selected and given all the authority necessary to have the individual’s gender identity and expression respected.

It is important that an individual, whenever possible, have an attorney complete these documents for them. The laws for these documents are complicated and vary by state; if they are not properly followed, the documents may be found invalid. Trans individuals and their advocates, families, and allies should be wary of downloadable online forms, which also do not account for the specific needs of trans individuals as described below.

Here are specific ways that the interests of trans individuals can be protected with healthcare planning documents.

Healthcare Power of Attorney (HCPOA)

An HCPOA is a legal document in which the Principal (the person executing the document) decides who will be their Agent (the one making decisions for them) if they are incapacitated and who may also have some immediate powers like being able to consult with the Principal’s doctors. Without an HCPOA, state statutes determine who is automatically granted decision-making power in the event of incapacitation. This will usually be a spouse, parent, adult child, or sibling. For many trans individuals, the person who would automatically be in charge under state law might not be accepting of their gender identity, or might be accepting but not competent at making sure that identity is respected. Even if the default decision-maker is a good fit for the individual, relying on the default is always a bad idea, because it can add
unnecessary confusion; furthermore, some providers may be prone to ignore the authority of a trans individual’s family member out of bias or malice, so it is best to have documents in order.

The HCPOA lists the powers that the Principal is giving to the Agent. The HCPOA can be written to explicitly give the Agent the power to order providers to respect the Principal’s gender identity and expression. Making this authority explicit will decrease the chance that providers ignore the Agent’s instructions because of discomfort with or ignorance about trans issues. Such language might read:

*The Agent has the authority... to direct any healthcare provider, medical staff, or other person to address me by my name and gender pronouns of choice, and to preserve to the fullest extent possible an appearance consistent with my gender identity.*

Advance Directive or Living Will

An advance directive – sometimes also known as a living will, and sometimes combined with the HCPOA into one document – gives instructions to providers as to how the individual would like to be cared for in an end-of-life scenario. It is always a good idea to have both an advance directive and an HCPOA because the HCPOA will ensure there is someone to carry out the individual’s wishes, while the advance directive will give added weight to the Agent’s instructions. It is especially important when, as is the case for trans individuals, there is a possibility that providers might be predisposed to ignoring the wishes of the individual out of bias, malice, or misunderstanding.

The advance directive addresses what should happen while an individual is in critical condition but still living. A section directing providers to respect one’s gender identity and expression could read:

*Respectful Relations*

*During any period of treatment, I direct my physician and all medical personnel to refer to me by the name of ________________ irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any transition-related medical treatment.*

*During any period of treatment, I direct my physician and all medical personnel to use the ________ pronoun in reference to me, my chart, my treatment, etc., irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any transition-related medical treatment.*

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During any period of treatment, if I am unable to personally maintain my 
________________ appearance, I direct my physician and all medical personnel to do so to the extent reasonably possible, irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any transition-related medical treatment.

Although advance directives technically lose effect immediately at the time of death – thus necessitating the need for a Disposition of Bodily Human Remains, discussed below – advance directives often include instructions in the event that the individual passes away. This is because it is often the first document on hand when death occurs, and it can give immediate (albeit not legally-enforceable) guidance. Such a section within the advance directive could be amended to say:

Respectful Remembrance

During any memorial service or preparation thereof, I direct all coroners, funeral home employees, healthcare workers, and participants to refer to me by the name of ______________ and the pronoun of ______________ irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any transition-related medical treatment. These individuals should also maintain my ______________ appearance, irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any transition-related medical treatment.

Disposition of Bodily Human Remains (DBHR)

As discussed above, the HCPOA loses its legal authority the moment its Principal passes away – meaning that once a Principal dies, the person who had been their Agent is suddenly powerless to act, and the advance directive’s instructions to service providers are no longer binding. It is therefore critical that trans individuals complete a Disposition of Bodily Human Remains (DBHR) at the same time as they complete an HCPOA, especially considering the sad history of trans individuals not having their final wishes respected by family members.

In short, the DBHR names the person who has authority over a deceased person’s remains. Naming someone in a DBHR does not prevent another family member from having their own memorial service, but it does prevent them from being able to decide on issues related to official wakes and burials, cremations, spreading or saving of ashes, etc. In most cases, an
individual will select the same person as Agent in the HCPOA as in the DBHR. For trans individuals, it is important that the person selected knows how they want their gender identity and expression to be respected and maintained (for example, how they should be made up and dressed before burial). As with the HCPOA, it is important that the person be a good advocate in working with service providers who may resist their instructions due to bias or ignorance.

The DBHR can be amended to explicitly grant the power to maintain the individual’s gender identity and expression. As with the HCPOA, this is important in proving to a reluctant service provider that this is what the deceased individual really wanted. Such a section might read like this:

Respectful Remembrance

During any memorial service or preparation thereof, I direct all coroners, funeral home employees, healthcare workers, and participants to refer to me by the name of ____________, and to use the ________ pronoun, and to maintain my ________ appearance, irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any transition-related medical treatment.

Conclusion

Please remember that all of these documents vary by state law, so knowing the law of the state is critical in successfully executing the documents (e.g., making sure there are appropriate witnesses, notarizations, etc.). The provisions above are examples that are designed for use in DC, Maryland, and Virginia, but that may not be exactly appropriate in every state. Thanks to the Transgender Law Center of California which has written sample legal documents on which some of the above provisions are based.