

Five Wishes
Compassionate End of Life Care
A Vocational Service Project from the Fellowship for Rotarian Healthcare Professionals
A Good Cause for Good Care
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In Rotary, there are five Avenues of Service: Club, Vocational, Community, International and Youth Services. The directive of vocational service is to increase members' knowledge and appreciation of various occupations, including ways to practice high ethical standards. The International Fellowship of Rotarian Doctors (IFRD, which includes all health care professionals) has decided as part of their vocational service to promote compassionate end of life care. We have named this program "A Good Cause for Good Care". In order to further this goal, we have partnered with the Aging With Dignity Foundation to promote the Five Wishes program with a grant from IFRD members to purchase one thousand of the Five Wishes documents. This document is normally US\$ 5.00 to download and use but because of the IFRD grant, Rotarians and their families can download Five Wishes for free.

Today I want to explain why promoting this program is so vitally important, and how it works, which will also illustrate how, through promoting high ethical standards, the IFRD is fulfilling its mandate for vocational service. It is a good cause for good care!

In my personal life, as well as my professional life as a registered nurse for 45 years, there are two things I can say with certainty; that people in general avoid talking about end of life issues, and that when an event happens that forces you to make decisions about yourself or a loved one, many people will automatically say "I want everything done" without understanding exactly what "everything" actually means.

The unrelenting march of technology has brought not only benefits, such as treatments for diseases and conditions which would have been fatal or caused lifelong disabilities in the past, but also created dilemmas where none existed before. The hard choices include pain control, artificial ventilation, tube feedings and dialysis, to name just a few.

Reports in the news about people who have lapsed into a coma or a vegetative state without documentation about their wishes, leaving family members pitted against each other regarding their care illustrate the need to have these unpleasant but very important discussions, and the Five Wishes program and document addresses these issues, making it easier for the person of your choice to be the guardian of the choices you wish to be made for your care when you are no longer able to make these decisions.

The Five Wishes document is legal in 42 states plus the District of Columbia. If your state is not listed in the instructions, you can still go discuss the considerations included in the instructions, and then have a lawyer draft a legally binding document that is approved by your state or just use the document to have a conversation with your family and healthcare team. Having a legally binding document is not essential to making your wishes known. The courts in the US are still arguing if unwanted quality of life achieved by unwanted medical care is problem. I will list the five wishes individually with a brief explanation and then provide a link for you to download the instructions and forms:

Wish #1
The Person I Want to Make Care Decisions for Me When I Can't

If there is no legal document stating who you are to have as a healthcare proxy – the person who can legally make decisions for you if you are incapable of making those decisions yourself – the laws will assign that duty to someone, usually next-of-kin. That could be a parent, child, sibling or spouse. All of these people can hold values different from yours. While you may value comfort care, even if that means you will be less aware of your surroundings and visitors, your family member may want to be awake and aware, no matter the pain and make that decision for you.

So the first criteria is that the person respect your personal choices and be willing to stand by them in the face of friends or family who might pressure them to go against your wishes. Well-meaning family or friends, and sometimes even healthcare workers, might try to pressure your proxy on various grounds, such as moral or religious reasoning, but it is important to have an open and honest discussion with your potential proxy about this. Going over all aspects of care as outlined in the Five Wishes document can guarantee as much as possible that your proxy will understand your wishes and advocate for you when the time comes. This also helps to diminish the confusion and bad choices that are sometimes made due to the emotional trauma to friends and family during such a situation.

If a person has had experience in this situation, or has medical knowledge, so much the better, and this person does not have to be a relative. A friend can just as well be a proxy as a relative and a legally binding document gives them the right to make those decisions.

Wish #2
The Kind of Medical Treatment I Want or Don't Want

This can encompass a multitude of things. From administering IV fluids or inserting a feeding tube to Do Not Resuscitate orders. Each person has their own set of ideas as to what treatments they would be willing to live with and those which they would not.

If you are not sure of all the treatment options that might be presented when the time comes, it would be a good idea to talk with your medical professional before having a discussion with your proxy, so that you and your proxy will both be aware of what choices might be offered, and which you would want accepted or rejected.

As for the Do Not Resuscitate order, that can be a bit tricky. At my last hospital, we were required to ask a patient on each admission if they wanted to be a DNR, regardless if they had signed one on a previous admission, since they could have changed their mind in the meantime.

I have had patients tell me, “Well the doctor can bring me back as long as I will be OK and not _____” (whatever their fear is). Since a DNR means if you stop breathing and your heart stops beating we do nothing, regardless of the possible outcome (with the exception of it happening during surgery), I had an alternate suggestion. I would suggest that they do not sign a DNR, but discuss this with their proxy, who could then make the decision when the time might come.

This is just one example of conversational topics regarding this wish.

Wish #3

How Comfortable I Want to Be

The word “comfort” includes many aspects of your life, including religious practices, hygiene, nausea, depression and pain, among many other things. The instructions for filling out the Five Wishes form lists many comfort measures which you might not otherwise think about.

Proxies should not assume that because a person has conducted their lives in a certain way, that in their final time of life, they would wish to continue exactly as before.

Wish #4 How I Want People to Treat Me

Again, every individual is different, and lifelong patterns and wishes may change when the end is near. Some people may wish to die at home, some people may wish to have their faith community present, and others may wish to be alone. My father went to church every Sunday for his whole life, but during his final days in the hospital, he did not want to see a priest nor did he want to receive Communion, but only wanted to have his immediate family around.

Again, the instructions try to cover as many scenarios as possible, and be aware that if the person’s feelings about anything in the document change, the document can be modified. There are instructions about modification included and should be read carefully, as should the entire list of instructions.

Wish #5 What I Want My Loved Ones to Know

This section should probably be read and thought about before discussing with your proxy. It includes how family and friends should think about you, how they might interact with each other before and after your death, care for the body after death (burial or cremation), funeral arrangements, etc. It is probably a good idea to discuss some of these things with the specific family members and friends ahead of time.

In conclusion, in this modern age of medical technology, it is more important than ever to have this discussion and retain control of your life through a health care proxy and legally binding document even at the time you are no longer able to make your own decisions.

You can access free the Five Wishes document Rotarians in Healthcare web site, look at the menu and go to a Good Cause for Good Care where you will be asked to complete a form as well as you can, send the form and an email will be sent to you telling you how to get your free Five Wishes Document.

<https://www.rotary-site.org/health-professionals>

(In addition, there is a similar document, but one that is created for adolescents and young adults. You can access information on that document here:

<https://www.agingwithdignity.org/five-wishes/pediatric/voicing-my-choices-faqs>)

