

FAST FACTS AND CONCEPTS #226 HELPING SURROGATES MAKE DECISIONS

David E Weissman MD, Timothy E Quill MD, and Robert M Arnold MD

Background Surrogate decision makers are often placed in the difficult position of making what feels to them as life or death decisions. This *Fast Fact* reviews an approach to help surrogates through the decision process when patients cannot participate in decision-making themselves.

Surrogate decision making The surrogate's role is clearly to exercise "substituted judgment" – that is, to make decisions as the patient would make them using the patient's values and preferences as previously expressed. The challenge was clearly expressed by the New Jersey Supreme Court in the Quinlan case: *if (the patient) could wake up for 15 minutes, understand his current medical situation completely, and then had to go back into it, what would he tell us to do?* In the case of children, surrogate decision makers (usually parents) are expected to make decisions that represent the child's 'best interests'; depending on the age and capacity of the child to participate in his/her own healthcare decision making, the applied 'best interest' judgment by the surrogate and healthcare providers may incorporate the patient's values and preferences to the extent possible, or may be solely based on the decision maker's interpretation of best interest. If there is conflict about what is in a child's best interest, or in cases of developmentally disabled adults who have never had capacity, consultation from ethics and law may be appropriate, as the rules governing decision-making vary considerably.

Helping surrogates

1. Before making a recommendation, make sure there is a common understanding of the patient's condition and prognosis. Following this, the next step is to try to understand the patient's goals in light of these medical facts.
2. Bring the patient's "voice" into the decision process even if he/she cannot participate directly: *If your father were sitting here with us, what would he say?* If available, share a copy of any advance care planning document with the surrogate. Realize that it is common for the surrogate never to have seen the document.
3. Whenever possible, frame the decision around the treatment goals (e.g. life prolongation, allowing a peaceful death) in light of the patient's current condition, rather than focusing on very specific treatments (e.g. thoracentesis, antibiotics). The details of the medical plan should flow from the overall goals of care.
4. Do not make the surrogate feel that they are taking full responsibility for medical decisions, especially those which may result in the death of their loved one (*We can do option a or b; what would like me to do?*). Once you have a sense of the patient's goals in light of his/her medical condition, offer to make a recommendation that reflects those goals. **Note:** Many families are looking for support and guidance from medical professionals, especially the physician. *Given what you have told me about your mother, and what we know about her medical condition, I would recommend....* Start with what you are going to do to achieve the patient's goals and then talk about what does not make sense given those goals. Remember, however, that some families may want information but not your recommendation. It is therefore important to offer your recommendation (*Would it be helpful for me to say what medically makes the most sense, given what you've told me about your Dad?*).
5. Remember that we are talking about the potential death of the surrogate's loved one. Emotions – sadness, frustration and guilt – are appropriate and to be expected. Use previously discussed emotion management skills to acknowledge, legitimize, empathize and support the family's emotional response (see *Fast Facts* #29 and #224).
6. Do not argue over the facts; repeating the facts over and over again is not likely to be effective. When the surrogate says *He is a fighter*, acknowledge that he is and has really fought hard. The surrogate saying *I want you to do everything* is as much a sign of emotional desperation as it is a factual request. Respond with empathy: *It seems this is really hard for you.* If hope for a miracle is expressed, it is appropriate to acknowledge that you hope for an unanticipated recovery as well, but that a miracle is truly what it would take at this point.

7. Rather than reiterating what medicine cannot do, consider using “*I wish*” statements to keep you in touch with the surrogate’s feelings, while simultaneously expressing medicine’s limitations (*I wish our medicines were more effective; I wish we had more medical treatment to offer than we do...*).
8. Recognize the importance of time and support for surrogates to do their necessary grief-work. Offer counseling services, either informal through the work of a palliative care team, or more formal resources available at your institution. Bring together your clinical care team and strategize potential resources for support such as chaplaincy, social services, psychology, palliative care or ethics consultation.

Remember that time is your ally. The surrogate needs to process that their loved one is dying and conceptualize what life will be like without him or her. This grief work takes time and psychological support. Often, letting people think about what you have said and talking again over subsequent days provides them the space to do grief work. It also allows them to see for themselves that what you have advised is coming true (e.g. the patient is not getting better).

References

1. Quill TE, Brody H. Physician recommendations and patient autonomy: Finding a balance between physician power and patient choice. *Ann Intern Med.* 1996; 125:763-769.
2. Quill TE, Arnold RM, Platt FW. "I wish things were different": Expressing wishes in response to loss, futility, and unrealistic hopes. *Ann Intern Med.* 2001; 135:551-555.
3. Fisher R, Ury W. *Getting to Yes: Negotiating Agreement Without Giving In.* Boston, MA: Houghton-Mifflin; 1981.
4. Quill TE, Arnold RM, Back A. Discussing treatment preferences in patients who want "everything". *Ann Intern Med.* 2009; 151:345-349.

Author Affiliations: Medical College of Wisconsin, Milwaukee, WI (DEW); University of Rochester Medical Center, Rochester, NY (TEQ); University of Pittsburgh School of Medicine, UPMC Health System, Pittsburgh, PA (RMA).

Version History: Originally published October 2009; copy-edited August 2015.

Fast Facts and Concepts are edited by Sean Marks MD (Medical College of Wisconsin) and associate editor Drew A Rosielle MD (University of Minnesota Medical School), with the generous support of a volunteer peer-review editorial board, and are made available online by the [Palliative Care Network of Wisconsin](#) (PCNOW); the authors of each individual *Fast Fact* are solely responsible for that *Fast Fact's* content. The full set of *Fast Facts* are available at [Palliative Care Network of Wisconsin](#) with contact information, and how to reference *Fast Facts*.

Copyright: All *Fast Facts and Concepts* are published under a Creative Commons Attribution-NonCommercial 4.0 International Copyright (<http://creativecommons.org/licenses/by-nc/4.0/>). *Fast Facts* can only be copied and distributed for non-commercial, educational purposes. If you adapt or distribute a *Fast Fact*, let us know!

Disclaimer: *Fast Facts and Concepts* provide educational information for health care professionals. This information is not medical advice. *Fast Facts* are not continually updated, and new safety information may emerge after a *Fast Fact* is published. Health care providers should always exercise their own independent clinical judgment and consult other relevant and up-to-date experts and resources. Some *Fast Facts* cite the use of a product in a dosage, for an indication, or in a manner other than that recommended in the product labeling. Accordingly, the official prescribing information should be consulted before any such product is used.