

Supplementary Data

SUPPLEMENTARY TABLE S1. POSITIVE FEEDBACK ON *CARING DECISIONS* FROM CONSULTATION PROCESS

Sample of quotes

- Looks fabulous ... valuable. The section on DNR was excellent. I found this confusing (i.e., their experience). Would love to have a copy of the final version. (couple)
- Accurate from my perspective. More importantly, I am extremely grateful that finally there will be some informative suggestions to families who have to face such decisions and it means that my daughter's battle to live does not go unnoticed to the professionals. (parent)
- It looks very good and should be a helpful resource. (parent)
- We both really like the initiative. Wish it was not just for online since I think it much more useful for the parents ... maybe that can be made into a book as well? (couple)
- Overall I think this is a great project and something that will be a huge help for some people. (parent)
- Well done, an outstanding job, you've been listening to parents who have been there. Impressed with section on euthanasia. (parent)
- Phenomenal document. I am very impressed! I think it will be a wonderful resource. (clinician)
- Love the book—a very important resource for families in crisis. (representative of religious group)
- It looks like a terrific piece of work to me and will no doubt be of great value to parents. (clinician)
- First, congratulations to everyone involved in putting together the handbook. For parents facing one of the most difficult decisions they may ever have to make, a resource such as this could be extremely helpful. This is an excellent resource which will be invaluable to families. (indigenous representative)
- Your approach is clear and yet sensitive, and there are some phrases and approaches that you have used that I feel are the best that I have seen anywhere to describe this incredibly difficult area of care. Congratulations on a really excellent set of information, which I'm sure will make a real difference to families. (international expert)
- I have not come across something as concise and useful as these documents. This is a magnificent work that helps to bridge the huge gap between the medical professional world and the parental perspective. ... Very useful—the religion, culture and life support chapter with short explanation of different viewpoints. At first my idea was that this was specifically useful for doctors and nurses and less for parents, but on second thought it helps you to get a bigger perspective, so it is well done. (international expert)
- I think this is an utterly outstanding piece of work! (international expert)
- It is a really important and thorough document. (clinician)
- Manual is very good and covers everything thoroughly. (clinician)
- Again congratulations to everyone for putting together such an informative booklet for families and a much needed resource. (support group)
- I enjoyed reading the handbook. (bioethicist)
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