

VIEWS & REVIEWS

PERSONAL VIEW

We must give children a voice in advance care planning

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Advance care planning (ACP) has become a key component of end of life care, but it involves far more than just conversations about whether or not to resuscitate. The wishes and preferences of the person concerned must be identified before they are too unwell to be involved in decision making. However, insufficient research and guidance exist on involving children and adolescents in advance care planning.

Retrospective interviews with the parents of children who had an advance care plan found the process helpful in assuring that the best care was obtained for their child, and in avoiding unnecessary suffering and preserving quality of life.¹ Perhaps unsurprisingly, these plans focused exclusively on medical interventions, covering decisions around resuscitation, artificial feeding, intubation and ventilation, antibiotic use, and admission to hospital. Parents reported “having peace of mind” and retaining a sense of control once they had signed the plan, but it is unclear whether their children experienced the same benefits. Were their wishes and preferences regarding medical and non-medical interventions identified and taken into account by those delivering their care?

Our daughter, Martha, had been receiving treatment for a life threatening condition for many years and was used to leaving hospital when there had been some improvement. When we realised that she was dying, we needed to explain to her why we were going to take her home even though her health had not improved. We anticipated that she was likely to ask questions, and we did not know how to respond. Supported by suggestions from the psychologist, I explained to Martha that if there came a time when she was not responding to treatment and would not get better, it would be best to go home.

She was an astute 9 year old, and she understood that this meant she was going to die, and wanted to know when. If I had not opened up the possibility of these painful conversations, Martha would not have experienced the joy she did in planning for a Christmas she was unlikely to see and could not have specified how she wanted her toys shared out after she died. She was able to request that I renew the dressing to her Hickman line after she died and that nobody else would touch it. I doubt I would have anticipated that this was important to her. However, her wishes made sense: they were consistent with how she had

treated her body during life, and my grieving was eased by knowing I could fulfil her requests.

For Martha, having her questions answered and her wishes and preferences sought helped to make her remaining life more manageable for her. Her fears were out in the open, and she was actively involved in decision making. We needed to know what mattered to her, and she needed to know that what mattered to her would be respected by us. In her dying Martha retained some of the control that was important to her.

As parents, we needed to have conversations with medical and nursing staff about resuscitation and care of the body after death, but we were too fearful. It is one thing to ask staff not to resuscitate an elderly parent, but it's different when it's your own child. Thankfully, with the advent of do not attempt cardiopulmonary resuscitation (DNACPR) forms, other parents won't be in the same situation. We knew what we felt was in our daughter's best interests but that it was not what the doctors thought, and were too afraid to ask. But are DNACPR decisions ever made without burdening parents with the details? If so, how can professionals know if parents have concerns or questions that remain unspoken?

More importantly, how are children given a voice? How are their views and preferences heard and taken into account? Are parents given the support they need in broaching these difficult conversations with their child? Are they equipped to discuss any unrealistic expectations their child might have? Research in Scandinavia has shown that many (but not all) parents whose child had died from cancer regretted not having spoken with them about death.² What support is available to help parents engage in these conversations?

If conversations for advance care planning retain their focus on resuscitation and withdrawal of treatment, other things of importance to the child will be overlooked. For advance care plans to promote quality of life, the child's wishes and preferences need to be sought, whatever they may be. It is only then that choice and control can be maintained.

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- 1 Hammes BJ, Klevan J, Kempf M, Williams MS. Pediatric advance care planning. *J Palliat Med* 2005;8:766-73.
- 2 Kreicbergs U, Valdimarsdóttir U, Onelöv E, Henter JL, Steineck G. Talking about death with children who have severe malignant disease. *N Engl J Med* 2004;351:1175-86.

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