

## Case Conference

### COMMENTARY

Dr Chris Parkin

*Moral Philosopher teaching ethics at Victoria University and Wellington School of Medicine*

A recurring but often overlooked principle in the Hippocratic corpus concerns knowing one's limitations. It expresses a key ingredient of a classical ideal of self-knowledge also accepted by Socrates. It is a principle the moral philosopher has to take seriously, for his or her role in the clinical decision-making context is strictly limited.

The moral philosopher may be able to assist with clarifying issues, ought to insist upon decent standards of justification, and must subvert uncritical adherence to prepared positions. But it would be ethically irresponsible for a moral philosopher to pronounce on Mark's future. She or he is at best a bit-player in a decision requiring multi-disciplinary consultation.

An immediate need is much more information. Setting aside the size of a wound that evidently stretches the bounds of credibility, many features of Mark's situation cry out for further elaboration: How early was the ultrasound finding made, and what prenatal follow-up was instituted? Why was awareness of cranial or cerebral abnormality not apparent until after birth? Why was delivery by caesarian section indicated? Just how severe was the less severe of the prognoses? Answers to these questions will contribute towards reducing the rather daunting elements of uncertainty present.

Some have held that coping with hard decisions requires an ethical division of labour. The physician's task, indeed duty, is adequately to disclose, and appropriately to explain, the options available. In Mark's case these include more than the extremes of palliative care or heroic intervention. The parent's task, perhaps right, is responsibly to select from the "shopping list" offered. Here we have professional beneficence within its proper

Following an earlier detection of spinabifida through an ultrasound scan, baby Mark was delivered by caesarian at full term of the pregnancy.

At birth Mark was found to have an enlarged head, as well as quite severe spinabifida. The defect was high on the spinal column and the wound was large: twelve centimetres long and three centimetres wide. The doctors could move his hips only slightly. The level of the lesion meant he would be unlikely to walk and will be incontinent; only his sensation seemed to be relatively spared. A scan on his brain showed other abnormalities and his brain's surface layer (the cortical mantle) was very thin, which suggested to some of

the doctors that he had very little chance of developing "personal human contact". However, medical opinion differed on this aspect, with some doctors predicting intellectual disability of a less severe kind.

The parents and the doctors needed to make a decision about appropriate treatment for Mark. Should the lesion be closed and antibiotics be given in the case of infection? Should a shunt be given to relieve pressure from his head? What path should they tread between all-out aggressive intervention (which might not be in Mark's best interests and impose too harsh a burden on him), and offering only comfort care, in the expectation that he might die quite soon from an (untreated) infection?

bounds co-existing with autonomous choice directed by good information. However, while there is an important grain of truth in the division of labour approach, it teeters on travesty. Its defect is to assume that physicians and parents are operating in more or less separate compartments, with all the risks of divergent value assumptions and impaired communication that compartmentalisation implies.

Closing Mark's lesion is not technically problematic. Similarly, the expertise for shunting, if that proves to be necessary and desirable, is at hand. There is no reason to suppose that prevention or control of possible infection will elude us. We can predict with confidence that Mark will be paraplegic and intellectually handicapped, though how severely so is less certain. We can state as realistically as we can what support may be available to Mark and those who care for him in future years, and, nowadays, its likely cost. Alternatively, we can sketch a largely reliable picture of what may follow if we elect to "let nature decide", or to intervene only under specified conditions. But all this wisdom is formulated within a compartment which cannot, from its own resources, interpret its meaning for Mark's life or that of his family.

The use of a plural is our only clue that Mark has two parents to help plan for his future. We know nothing about the strength of their relationship or the nature of their family commitments. Does Mark have siblings? If so, how many are there? What do we know about them? How is their upbringing affected by Mark's joining the family?

We also need to know something of the family's socio-economic circumstances; and their beliefs and values. Was termination considered at an earlier stage? If so, what were the considerations which led to its rejection? It is crucial to understand something of the framework of values within which Mark's parents are struggling to come to terms with the decisions to be made. Their situation puts them under pressures of which Mark's likely functioning may be but one.

Mark's parents will consider his best interests as part of their overall commitments, which may be many and complex. The time and energy his needs may deserve nonetheless affect, for good or ill, how they can respond to other legitimate demands upon them, not least those of other family members. These demands must be effectively communicated to members of the team caring for Mark, who need to keep in mind that his parents are the experts

about those facets of the case. They have the tough job of trying to work out what they can manage, not necessarily as the overriding consideration but because their knowing their limitations materially affects the extent to which Mark's best interests can in fact be realised.

Mark's parents need to be seen as members of the decision-making team, not as outsiders negotiating with it. Their expertise embraces the home environment in all its complexity, and they will need to listen to and be guided by the technical and other expertises represented in a multi-disciplinary team. Nancy King has recently commended more "transparency" in interactions between doctors and patients. The intent is to make the reasoning behind diagnosis, prognosis and management plan transparent. Uncertainties, false leads and dead ends are declared alongside grounds for optimism.

But King envisages transparency as a one way process. The grain of truth in the division of labour perspective commends transparency as a two-way, or more likely in reality a multi-way, process rather than a stakeout of patches to be defended against would-be intruders.

Whatever its shortcomings, the Hippocratic Oath envisages a doctor dedicated to patient wellbeing, a doctor who recognises the boundaries of his (sic) competence and operates within them, though hopefully constantly expanding them. Perhaps the hardest lesson to learn is to judge when "physic is of no avail". In those situations, and Mark's may be a modern counterpart, the bounds of what is possible may no longer match the bounds of what is desirable.

Plotting the human significance of that divergence is an unenviable task. But if those involved know their own, and others', limitations, they are arguably, if perhaps paradoxically, better placed to harness their individual strengths in a genuinely collective sharing of resources which contributes to the best decision on the day.

## COMMENTARY

Ms Phillipa Wilson  
*Green Island, Dunedin*

I relate to a lot of the issues of Marks case.

Mark's defect is about the same size as mine, however my own is on my waistline, not as high as Mark's. My lesion was not closed. I would have preferred it to be because it is very sensitive, sometimes gets knocked and is then very painful. However when I was born there was not the information that is available today.

I was expected to live only five days. Thirty-five years later I'm still here. I am told I was a very sickly child until I was about seven. Mainly I suffered from kidney and bladder infections. Now I know how to look after myself and the signs of these problems. My head was not enlarged.

Now I live a very full and active life from my wheelchair. I drive my own car, keep house myself and do my own garden. I have a very active seven year old son. I had him by caesarian section. He had to be delivered at 29 weeks gestation because my blood pressure was extremely high and I had kidney problems, but these problems can occur with any pregnancy. I support my husband and son in their many activities. I do community work for Dunedin C.C.S. and attend Polytechnic.

The parents should make the final decisions that will have to be made about Mark's future. I believe the parents should be given all the necessary information and advised fully on the procedures, implications and benefits of all treatments. They should be kept up to date with appropriate information, and referred to other people if necessary. Hearing about other cases can be very helpful and encouraging.

I believe Mark should be given the fullest medical attention he may need to be able to live a full and active life. If Mark's lesion was to be closed and an infection did enter the spine then antibiotics should be given. If it is necessary for a shunt to be put in place, then so be it.

The concerns regarding Mark's intellectual ability are only an opinion and I know people who cannot maintain personal human contact who do not have spinabifida. There are agencies available that could help if it was necessary.

I believe if Mark's parents take each day as it comes and know where to get the appropriate support services there is no reason why Mark couldn't live a full life.

Life is not easy but with the appropriate support and help it can be done.

## COMMENTARY

Dr Brian Darlow  
*Senior Lecturer in Paediatrics Christchurch School of Medicine*

In considering this case the first priority must be to establish an accurate diagnosis so that as accurate a prognosis as possible can be made. We are given only brief information; the defect is "high", but how high exactly; "his sensation seemed to be relatively spared", but what is the sensation level; "his brain showed other abnormalities", but what are these and are they the cranial changes seen in most infants with myelomeningocele? Are leg deformities present and are there other important abnormalities including chromosomal anomalies? Diagnostic aids such as cranial CT scanning may be required. All members of the team to be involved in caring for Mark, in our hospital usually a neonatologist, developmental paediatrician and neurosurgeon, will contribute to this diagnosis and once established the information should be recorded in the note.

The second priority is to share this information with the parents. To do this effectively they must have time and space for their own grieving process. Ideally the information should be given by the paediatrician who will care for the child long-term and to both parents together with their child present.

The third priority is for the team, including the parents as part of that team, to make decisions with regard to the next steps in management. The decisions should be reviewed in the light of time and the parents feelings, the child's development and changing clinical evidence.

I believe the paediatrician must enter this process as the advocate for the child, considering what is in the child's best interests. The principal of nonmaleficence, "first do no harm", is paramount. In addition I freely admit to comparing opinions and decisions (mine and those of others) against the yardstick of what I would wish as a parent for my own child.

Some broad comments about myelomeningocele can be made:

- Survival is lowest and disability greatest when the sensory level is above T11.
- In the 1970s, John Lorber propounded "adverse prognostic criteria" (gross paralysis of the legs, thoracolumbar lesions, kyphosis or scoliosis at birth, gross hydrocephalus, intracerebral birth injury) any of which predicted early death if treatment was withheld. However, it has not been the experience of other centres that these criteria are universally valid either as predictors of death or of unacceptable outcome.
- Even with surgery many infants with severe hydrocephalus at birth and thoracic lesions will die.
- Even without surgery many infants with large back lesions do not die.
- Treatment options have altered considerably in recent years with ventriculo-peritoneal shunts, clean intermittent catheterisation, surgical techniques for kyphosis and closing the back defect, all greatly enhancing the long-term outlook.
- Recent follow up studies suggest even the most severely affected children who have survived do not consider life to be intolerable.

Weighing up the clinical data, and there are inconsistencies in the picture we are given which means the prognosis for Mark is difficult to predict, I would advise deferring surgery in the first instance. Many parents do wish to delegate responsibility for decisionmaking to medical advisors, particularly when the interests of the child are best served by withholding active treatment. If this was the team advice and it was accepted by the parents, then provided the circumstances seemed appropriate I would encourage them to take Mark home to be part of their family. Full support can continue to be given to them. As far as feeding is concerned, I am always uncomfortable with "feeding on demand only" and would give tube feeds as necessary. Equally, if the hydrocephalus became severe and distressing to Mark and his family, I would advocate shunting. Both procedures may prolong life but are in accordance with the principal of nonmaleficence.

Perhaps because of lack of information, it seems to me that this case falls into a category where treatment could be considered optional. As such it is particularly important to ascertain the parents wishes. If, for instance, despite the advice against active treatment they wished for "all to be done" (as is suggested they might given the decision to deliver by Caesarean section) I should have no difficulty with this. Parents, in my view, do have some autonomy in decisionmaking, but only insofar as their decisions are reasonable by the moral values of society.

### Postgraduate Opportunities

As part of Otago University the Bioethics Research Centre is able to offer postgraduate opportunities for students from a wide variety of disciplines.

In 1993, supervision is available for the doctoral programme, and for a DipGrad. In 1994, it is hoped also to offer a degree in Bioethics at Master's level.

The Doctor of Philosophy degree is open to graduates in any relevant field who can show evidence of research ability. The minimum residence requirement is 18 months.

The DipGrad (Bioethics) programme offers papers in Theories of Biomedical Ethics, Clinical Aspects of Biomedical Ethics, Moral and Social Philosophy, Law and Medicine, Pastoral Theology, and further special topics.

The DipGrad is open to graduates with a degree or diploma from a New Zealand University, or with an equivalent non-university qualification plus relevant work experience.

Applications for the Ph.D. can be made at any time and enquiry should be addressed to the Director of the Bioethics Research Centre (address below).

Applications for DipGrad must be in by 1 November 1992. Enquiries can be made to:

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