Medical Treatment – The Child's Right to Decide

Dr Kenneth Nunn trained in Medicine at the University of New South Wales when it was considered an inferior university, moved to train in psychiatry at the University of Newcastle when it was considered foolish to do so and subsequently trained in London in child psychiatry, when it was generally considered that British medicine was past its peak.

He recidivistically returned to Newcastle and did his PhD on the Measurement of Hope in the medical faculty. He has since taught in the universities of London, Sydney, Newcastle and New South Wales and has held various major posts in heading up child psychiatry services in New South Wales, where he has been spectacularly unsuccessful in leading to lasting reform for the care of troubled children.

He now works in the Bronte Adolescent Forensic Intensive Care In-patient Unit at the New Forensic Hospital at Malabar and enjoys the status of an old clinician who is seeing out his dotage doing what he likes most – seeing young people who continually give him more grey hair. He is a reluctant and curmudgeonly Fellow of the surviving medical guild systems, which still claim Crown patronage – the Royal Australian and New Zealand College of Psychiatrists and the Royal College of Psychiatrists.

He has written extensively on subjects relating to the brain and behaviour which have sold in limited copies, many of which he has bought himself, and has received excellent reviews of his books in journals which are largely not read. He enjoys a wonderful medical collegium in Justice Health and continues to smile in the face of a Sisyphean struggle against his obsolescence.

In the *Gospel according to Peanuts*, Linus argues in his self-defence,

"I love mankind, it's people I can't stand".

If this discussion were to be about universals, I would commence with the vulnerable nature of childhood and the importance of children for our future. I have, after all, been seeing troubled children for the better part of thirty years. It seems likely that I will agree with both propositions – namely, that children are vulnerable and that children are important.

The late development of the human brain

There is considerable debate about when the developing human becomes human and, therefore, subject to the rights and protection of fellow humans. For what it's worth, just to clear the air and to add an ethical *frisson* to the evening, I should say that the human brain is operating at full, co-ordinated, 'human capacity' at between 25 and 35 years. This might, in extraordinary circumstances, still be the case at 45 years. All is suboptimal, in one way or another, outside of this window of human apogee. This means that, even at this early stage in my talk, you must consider whether anything I say may not represent the fractured outputs of a fragmented grasp on an altogether ethereal subject by a declining intelligence, fallen from the full expression of humanity.

Are animals better protected than children?

Of course, this begs the question, all too often avoided, as to whether we might not be better to establish that children qualify as animals, thereby meriting protection under altogether different legislation and with a different justification. In relation to our present topic, it is worth noting that the high level of medical treatment available through veterinary services in New South Wales raises the very serious possibility that, were medical services organised with the same level of professionalism and concern for 'the client', we would effect a major advance in the provision of community well-being in childhood.

The exceptionalism of every child

With these matters understood as the limits of our subject and my presentation, let me proceed to relinquish the great matter of universals, and consider how the particularities of a child's brain development and environmental experience might or might not provide the underpinnings for the exercise of decision-making. The invisible world of the great and compelling universals is invariably made messy, grubby and altogether untidy by the irregular verbs of childhood and the endless list of exceptional circumstances, necessary amendments and addenda which ruin our attempts at unsullied aspirations. Individual children, on the other hand, we deal with every day.

Decision-making occurs in a particular place

In case my point is lost by my very particular examples, it is simply this: decision-making of any sort does not occur in a space untouched by material considerations. It occurs in a very little space of between 1 and 1.5 litres and, even within that small space, within an even smaller and defined space of around 300mls in the

front of the brain. Decision-making takes place within very real constraints of time and capacity. Decision-making is a high-order cerebral function. It has underpinning biological mechanisms in humans and in all mammals, taking place when those mechanisms are in place and not occurring when they are absent.

Decision-making has particular biological needs

Decision-making depends on oxygen and glucose, delivered by blood vessels to neurones which have been fearfully and wonderfully crafted out of the threads of the periodic table throughout antenatal development. But more generally, this carbon-based tapestry has emerged over the 500 million years since life went multi-cellular and nervous systems were needed to communicate between the trillions of cells which make up bodies such as our own, in order to form the 'parliament' of the self. The many elements of this disparate 'self' do not always agree with one another. They frequently conflict, staying together only because there is no independent existence outside of the community of the body. The idea of a harmonious, monolithic self is a necessary fiction required to proceed with daily life. Even within the nervous system, the loudest voice often prevails in the making of a decision. But it is not a solitary voice and no Act of this Parliament - a decision - goes undebated, uncontested or passed without amendments.

Understanding the options

These represent the material pre-conditions of decision-making. Any decision-making presumes that there are options to be chosen and that these options are known and to some degree understood. The words 'understood' and 'understanding' are not the parlous and shallow notion currently sought out by me and my colleagues to satisfy the lowest interpretation of the Presser criteria for Fitness for Trial – an understanding robbed of its emotional appreciation, its capacity to inform reasoning and to take account of consequences and to participate in the decisions of defence. This notion of understanding is little more than rote learning. Most intellectually normal five-year-olds can be taught to satisfy these criteria, so defined.

Decision-making with comprehension

The right to decide - or to contribute to a decision - without available, acceptable and comprehensible options, remains an abstraction which most children are likely not to understand nor appreciate as they attempt to reason, to chose what they value and to avoid what they fear. In short, any decision-making – let alone decision-making in children, especially decision-making involving medical treatment – is a very particular enterprise. Attempting to understand such an enterprise should not be entered into 'lightly or inadvisedly'. Our decisions about children's decision-making are fraught with consequence. These are consequences which most adults do not appreciate and anticipate will change the manner in which we reason and apply our values in our decisions surrounding children.

The sensory date of decision–making *in utero*

The building blocks of decision-making are assembled in the first twenty weeks of pregnancy. Those parts of the brain which enable sensory information – the data of experience – to be taken in and processed and decided upon, come on line first: the visual cortex for seeing, the auditory cortex for hearing, the somato-sensory cortex for touch, pain and temperature, the olfactory cortex for smell and the gustatory cortex for taste. "Nothing is in the intellect that is not first in the senses" (Aristotle). These sensory portals into the theatre of the mind, where decision-making takes place, will mostly be operational within the first six months of extra-uterine life.

I should just say that the words 'mind' and 'brain' are confusing unless you use them in the way that many neuroscientists use them today. That is to say that 'mind' is to 'brain' as 'flight' is to 'wing', or 'digestion' is to 'stomach'. That is that 'mind' is function and 'brain' is structure. The old chestnut of the mind-brain problem then becomes a linguistic problem, the problem that we made 'mind' a noun and not a verb. Mind is what brains do.

The binding of the senses with instinctive and habitual response

The sensations are brought into the brain and then bound together and with an immediate response – those responses that are instinctive and habitual – so these senses will be integrated in a number of key areas in the brain to bind together our sight, our hearing, our touch, our smell and our taste into a single coherent experience. We take for granted that, when you are watching me, my words occur at the same time in sound as they do in vision and that, if I were jumping up and down and causing vibrations on the floor, that these, too, were connected. That integration is carried out in very particular parts of the brain. These centres continue to integrate with motor activity and they mature over of the first decade of life.

Some of these integration points will bind together deep patterns of instinctive and habitual response, our fears and desires with factual data, in order to avoid harm and seek good.

Memory and emotions

But there will be more than instinct and habit in the emergence of decisions. Memory – learned, archived and retrieved – in the temporal lobes will, in time, allow the accumulated past to guide an uncharted future. A life without memory is unable to be traversed in a meaningful humanity. Memory does not arrive as a gift from Mount Olympus, intact and fully-grown. It is slowly acquired, slowly aggregated and integrated into the fabric of the self. As this happens, the capacity to decide emerges and grows with the using, like eagles' wings, on the perilous cliffs of experience. It is sometimes forgotten that our memory systems are deeply enmeshed in our emotional systems. Emotional systems are the long-term mechanisms for short-hand decision-making which Nature has vouchsafed us from a 3.8 billion year history of life. Far from always being an unnecessary interference in decision-making, our emotional responses provide the contours of our value systems, in the absence of which we are unable to effect any substantive, humanly relevant decision. These decision-making centres are very vulnerable to infections such as herpes encephalitis, rubella and meningitis and to perinatal trauma. They are also sensitive, after birth, to life-threatening traumas – such as physical and emotional abuse, leaving indelible sensitivities to future threats. The concept of decision-making stripped naked of memory and emotion is also a fiction, though by the end of my talk I hope that I will have caused you to question whether it is a necessary one.

The executive role of the frontal lobes in decision-making

We have seen the emergence of the senses. We have had the binding of the senses together with instinctive and habitual responses. These have been, with memory and emotion, woven into their fabric. Finally, the capacity to hold the data of sensation, the focus of attention, the weight of emotion and the guidance of memory and to formulate a meaningful response, falls to the frontal lobes, which act as the Speaker of the House and execute the final vote and decision.

If sensation and perception capture the present, and memory and emotion capture the past, then here in the frontal lobes the future is anticipated. These are the centres of the brain, which mature most slowly and will not be fully connected and operational until the middle of the third decade – around twenty-five to thirty years of age. They are also the most vulnerable.

Alcohol and brain development

It is now conservatively estimated that 1% of all live births have had alcohol-related neuro-developmental disorder in utero (ARND) a massive expansion on the previous notion of fetal-alcohol syndrome, prompting the World Health Organisation to issue warnings on the use of any alcohol during pregnancy. Alcohol preferentially damages the developing key integrative building block of the future decision-making mechanism – the frontal lobes – leading to severe attention deficit disorders with lives heedless of consequence.

More generally, all of the causes of intellectual disability and disorders of the developing brain are associated with a reduced capacity of the frontal lobes in a conservatively estimated 5% of the population. This 1 in 20 children is considerably greater in those with chronic medical ilnesses, especially involving the central nervous system, such as epilepsy and in the detained juvenile population. Of the approximately 450 children in detention at any one time in New South Wales, it is difficult to reduce the figure with neuro-developmental difficulties, with major impact upon decision-making, to less than 20% ie 90 children but this is almost certainly an underestimate, especially in view of the younger and younger ages at which detention is occurring.

Decision - making in relation to walking and talking

Let us move out of the womb for a little moment and move to decision-making in relation to walking and talking by way of an illustration of a principle.

The right to walk has, as a precondition, the capacity to walk. This involves the myelination (or insulation) of the long nerves from the brain to the legs, which takes place towards the end of the first year of life, together with the ongoing development of connections between different parts of the brain which enable coordination.

The right to talk presupposes a capacity to communicate. Communication options enable options of choice for decision-making. So many choices are not even conceivable without the capacity to communicate with others. Martin Luther King's comment during the civil rights era, on the right to vote in Alabama versus New York is

apposite. In Alabama, a black man could not vote, while in New York there was nothing worthwhile for which a black person could vote. Capacity and options are both preconditions for decision-making.

Decision-making in relation to schooling and friendships

There is something much more obviously self-evident about the capacity to walk and talk, as opposed to the capacity to mix socially in a school and to have friendships. In reality, social relationships and rules are much more complex and high-order. Even very capable professionals might have difficulty making and maintaining friendships. The brain mechanisms underpinning social skills and friendships – now summarised in the shorthand among neuroscientists as the social brain – are very subtle and only available to the higher mammals and primates, including humans. Not all social ineptitude and lack of friendship is due to brain disorder or dysfunction. However, if these areas are compromised within the social brain, social ineptitude and lack of friendships are the rule, not the exception. Very many decisions relating to medical treatment involve the capacity to relate and to understand social communication.

Decision-making in relation to love and children

It may not be immediately obvious that the decisions of childhood should involve matters of love and child-bearing. However, contraception, treatment for human papilloma virus, chlamydia and other sexually transmitted diseases, and termination of pregnancy, are all major themes of early adolescence in vulnerable populations, from late childhood and early adolescence. The decisions to have sexual relationships, enter into lasting relationships and have children, might fall very far short of the biological capacity to do so. Here we have the opposite problem to that encountered previously in this talk. Up to this point I have emphasised that capacity has been a pre-condition to consent. Now we have some capacities not matched by corresponding emotional, social and moral development. The thinking brain, the emotional brain, the social brain and the sexual brain might all mature at very different rates and give rise to unwieldy chimeras – monsters of uneven development - of decision-making capacity. Most animals are capable of having sex and offspring. Most of them have very little decision–making capacity. Sometimes capacities in adolescents, such as sexual development and peer relationships, drive decisions beyond the emotional, social and moral capacities required for decision-making.

Decision-making in relation to dying

The place where medical decision-making in childhood seems most poignantly ambiguous surrounds death. Over the years, I have been involved in a great deal of work with children with fatal diseases. Here, the concept of death can be very limited and, in very small children, not very different from sleep and saying a temporary 'goodbye'. However, here too an understanding of brain function after radiotherapy, chemotherapy, or primary or secondary spread of malignancy might affect the very mechanisms of decision-making.

For many children, relief from pain and nausea and the presence of parents and loved ones informs whatever options are available. Mostly children do not want to distress their parents or leave them without comfort and hope. Here, too, the self-soothing of the brain with its intrinsic opioid release and its capacity to 'go to another place' by dissociating from the present, may be crucial as decisions are demanded for further treatment or treatment which, by its very duration and intrusiveness, becomes unendurable without such mechanisms. The paradox is that the Gillick criteria are actually less likely to be adequate in the very populations where we are raising these questions.

Conclusion

If we are to recognise, assert and defend rights, we must establish the preconditions for those rights to be exercised; namely the underpinning brain capacities to exercise them, an emotional and social environment which facilitates such an exercise and the presence of options for those rights to be meaningful. Immanuel Kant reduced the nature of philosophy down to three great tasks or questions: "What can we know?" "What ought we to do?" and "For what can we rightly hope?" There is much that is very particular about the decision-making of children. But there is one common, or possible, universal, which might be discernible amidst all the particularities of childhood. It is the right to hope for oneself and for those one loves. It is the right to use every means at our disposal to bring to fruition whatever brain mechanisms the child possesses to make decisions. It is the creation of options to make this right, however abstract, a reality.