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EDITORIAL

The Right to Sue for Non-Communication or Delay in the Diagnosis of Neurodegenerative Diseases – *Ian Freckelton QC*

Delay in diagnosis of neurodegenerative diseases can be caused by clinical factors such as the lack of recognition of symptomatology as attributable to the disease or confusion of symptoms with those from other conditions. A number of studies have shown that psychiatric symptoms may precede motor symptoms and the ultimate diagnosis, in substantial part because they may mirror symptoms arising from other aetiologies. Any delay in diagnosis of relatives with neurodegenerative diseases and failure to communicate such a diagnosis can have very significant adverse effects for provision of treatment and for decisions made which can result in the passing on of the disease. In turn such decisions made in the absence of information can cause significant distress which in its own right can be counter-therapeutic. This article reviews two important decisions made by the High Court of England and Wales in 2015 and 2016, *ABC v St George's Healthcare NHS Trust* [2015] EWHC 1394 and *Smith v University of Leicester NHS Trust* [2016] EWHC 817, in which rights to sue were denied in the scenarios of failure to disclose neurodegenerative heritable symptomatology to relatives. In both decisions it was decided that no negligence was engaged in by a failure on the part of health professionals to disclose their knowledge of a person's neurodegenerative condition to relatives of the person, in spite of the fact that failure to do so would foreseeably cause harm. This editorial argues that so doctrinaire an approach to the ethical obligation of confidentiality is counter-therapeutic and needs to be reconsidered.

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LEGAL ISSUES – *Editor: Danuta Mendelson*

“My [Electronic] Health Record” – Cui Bono (For Whose Benefit)? – *Danuta Mendelson and Gabrielle Wolf*

We examine the operation of Australia's national electronic health records system, known as the “My Health Record system”. Pursuant to the *My Health Records Act 2012* (Cth), every 38 seconds new information about Australians is uploaded onto the My Health Record system servers. This information includes diagnostic tests, general practitioners' clinical notes, referrals to specialists and letters from specialists. Our examination demonstrates that the intentions of successive Australian Governments in enabling the collection of clinical data through the national electronic health records system, go well beyond statutorily articulated reasons (overcoming “the fragmentation of health information”; improving “the availability and quality of health information”; reducing “the occurrence of adverse medical events and the duplication of treatment”; and improving “the coordination and quality of healthcare provided to healthcare recipients by different healthcare providers”). Not only has the system failed to fulfil its statutory objectives, but it permits the wide dissemination of information that historically has been confined to the therapeutic relationship between patient and health practitioner. After considering several other purposes for which the system is apparently designed, and who stands to benefit from it, we conclude that the government risks losing the trust of Australians in its electronic health care policies unless it reveals all of its objectives and obtains patients'

consent to the use and disclosure of their information. 279

MEDICAL ISSUES – *Editor: David Ranson*

The Foundations of the Comparison Forensic Sciences: Report of the President’s Council of Advisors on Science and Technology – *Stephen Cordner, David Ranson and Richard Bassed*

In September 2016, the President’s Council of Advisors on Science and Technology (PCAST) in the United States published its report to the President entitled *Forensic Science in Criminal Courts: Ensuring Scientific Validity of Feature-Comparison Methods*. The need for this report arose out of the highly critical 2009 National Research Council report on the state of forensic sciences in the United States. The report had noted that there were particular problems in feature-comparison disciplines where the science underpinning the validity of the discipline was poor. The PCAST report has developed the National Research Council’s thinking further. It looked at the foundational validity of a number of forensic disciplines, including, for example, bite mark interpretation in forensic odontology. PCAST concluded that bite mark analysis does not meet the scientific standards for foundational validity. In addition, it felt that the prospects of developing bite mark analysis into a scientifically valid method were poor, and they advised against government investment in research to try to establish such validity. The principles discussed in this report, focused as they are on forensic science, will need to be digested by forensic medicine. Forensic medicine will be increasingly called upon to justify the validity of the various areas in which its practitioners provide expert evidence. 293

BIOETHICAL ISSUES – *Editor: Grant Gillett*

Error and Accountability in a No-Fault System: Maintaining Professionalism – *Rebecca Babcock and Grant Gillett*

No-fault systems of dealing with medical error have been mooted but are often criticised for removing or blunting professional accountability. An analysis of contemporary health care and the systems approach to medical harm suggests that the criticisms are misplaced. A no-fault system in fact encourages correction of harm and prevention of injury due to systems and personal professional error. It removes an unhealthy climate of name, shame and blame, and an unrealistic image and set of expectations on health care professionals. By contrast a tort-based system fosters bitterness and an adversarial forensic lottery that perpetuates harmful practices and does little to identify and analyse the causes of misconduct and injury. What is more, a tort-based system can remove direct incentives for personal and institutional change through third-party risk sharing that mitigates any penalties on those who need to change their behaviour. Thus the criticisms of no-fault systems to deal with medical harm draw on populist but ill-thought reactions to a problem that can cause truly awful damage to both patients and the professionals who try to help them. 299

MEDICAL LAW REPORTER – *Editor: Thomas Faunce*

Seeding Australian Regulation of Genomics in the Cloud – *Elizabeth Abbott and Thomas Faunce*

Cloud computing has facilitated a revolution in genome sequencing. As big data and personalised medicine increase in popularity in Australia, are the legal and regulatory regimes surrounding this nascent area of scientific research and clinical practice able to protect this private information? An examination of the current regulatory regime in Australia, including the *Privacy Act 1988* (Cth) and medical research laws that govern cloud-based genomics research highlights that the key challenge of such research is to

protect the interests of participants while also promoting collaborative research processes. This examination also highlights the potential effect that the Trans-Pacific Partnership Agreement's Electronic Commerce Chapter may have had on using the cloud for genomics and what the consequences may have been for researchers, clinicians and individuals. Lessons learnt here will be relevant to studying similar impacts from other trade and investment agreements such as the Trade in Services Agreement (TiSA). 310

ARTICLES

Is Australia Well Equipped to Deal with Future Clinical Trials? – *Lisa Eckstein and Don Chalmers*

The French Biotrial tragedy highlighted the potential for healthy volunteers to suffer tragic injuries in clinical trials and the need for clear and effective regulatory oversight. The Australian system for approving clinical trials has been reviewed continually over the past three decades, resulting in a considerable degree of deregulation. Approval to commence a trial largely depends upon assessment by voluntary Human Research Ethics Committees (HRECs), without much government oversight of the investigational products or trial procedures. Once a trial has been initiated, ongoing review of its safety is conducted by Data Safety and Monitoring Boards (DSMBs), which operate largely outside the boundaries of Australian or international regulations. Australia should carefully audit its regulatory frameworks for ensuring the safety of participants who consent to enrol in clinical trials. 333

Is There a Role for Law in Medical Practice When Withholding and Withdrawing Life-Sustaining Medical Treatment? Empirical Findings on Attitudes of Doctors – *Lindy Willmott, Ben White, Malcolm Parker, Colleen Cartwright and Gail Williams*

The law regulates many aspects of decision-making around the withholding and withdrawing of life-sustaining medical treatment from adults who lack decision-making capacity and are approaching the end of their lives. For example, it governs whether an adult's advance directive is binding and applicable and, if not, who is authorised to make the treatment decision and the criteria that should guide the decision. Doctors who treat patients at the end of life should be aware of the prevailing law so that they can practise within those legal parameters. However, the law in this field is complex and challenging for doctors to know and understand. Doctors will be prepared to invest time into learning about the law only if they believe that the law is worth knowing and that practising medicine in a legally compliant way is a desirable goal. This article provides insight into doctors' attitudes about the role of law in medical practice in this field, and argues that education is required for doctors to reconceptualise knowledge of the law as constituting an integral component of their clinical expertise. 338

The Knowledge and Practice of Doctors in Relation to the Law That Governs Withholding and Withdrawing Life-Sustaining Treatment from Adults Who Lack Capacity – *Ben White, Lindy Willmott, Colleen Cartwright, Malcolm Parker and Gail Williams*

Law establishes a framework for making decisions about withholding and withdrawing life-sustaining treatment from adults who lack capacity. However, to what extent do doctors know and follow this law? This article reports on a three-year empirical study that sought to answer these questions. The research found that doctors have significant legal knowledge gaps in this area. It also found that doctors do not attach significant weight to legal considerations in their decision-making. This article argues that law does have a role to play in end-of-life care. However, law reform is needed to make the law more accessible, medical education needs to be improved, and a change in attitude by doctors to medical law is required. 352

Decision-Making Capacity and its Relationship to a Legally Valid Consent: Ethical, Legal and Professional Context – *Scott Lamont, Cameron Stewart and Mary Chiarella*

Decision-making capacity has been researched from within the disciplines of bioethics, medicine and law. The field of capacity assessment is dominated by tension between the principles of autonomy (self-determination) and beneficence (protection). Further, decision-making capacity is argued to be the central component of a legally valid consent. This article discusses the relevant ethical, legal and professional responsibilities relating to decision-making capacity and consent to treatment within health care. It begins with an overview of the ethical principles underpinning decision-making capacity and consent, and follows with a legal analysis of these concepts, focusing on the common law of trespass and negligence. The article then explores the concepts of best interests and necessity, which underpin the treatment of incapacitated persons, before concluding with an examination of treatment refusal and legislation relating to decision-making capacity and consent to treatment.

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Balancing Self-Tracking and Surveillance: Legal, Ethical and Technological Issues in Using Smartphones to Monitor Communication in People with Health Conditions – *Jacki Liddle, Mark Burdon, David Ireland, Adrian Carter, Christina Knuepfer, Nastassja Milevskiy, Simon McBride, Helen Chenery and Wayne Hall*

Smartphones are being used to track the health of individuals in their own environments. For example, a smartphone app could be used to monitor the impact and progression of Parkinson's disease, as well as indicate whether treatments may need to be adjusted, based on an analysis of voice and discourse. The app uses smartphone audio sensors to detect when conversations are taking place and activates an app to record the conversation. But what happens if a background conversation is also collected by the recording? The participants of the background conversation are unaware of and have not consented to the recording. Unauthorised recording could also raise legal issues under surveillance devices legislation and has ethical implications. It is a complex task to balance the potential benefits of self-tracking of health conditions to consumers and the health system, with the legalities and ethical issues related to privacy. The health-related monitoring industry is moving so rapidly that current legal and ethical processes and protocols may fail to balance these concerns. This article explores Australian legal and ethical perspectives on how to achieve the potential benefits of these technological approaches while preserving privacy.

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Primum Non Nocere: A More Proactive Workplace Drug Testing Regime for Australian Medical Practitioners? – *Claire Leyden-Duval*

This article considers whether Australian medical practitioners should be subject to a more proactive workplace drug testing regime in order to minimise the risk of harm to patients. It first canvasses the history of workplace drug testing in the United States, the United Kingdom and Australia, before exploring whether there is a need for more proactive drug testing of Australian medical practitioners. It then considers whether workplace drug testing adequately addresses drug-related risks to patient safety, and discusses some of the privacy issues associated with workplace drug testing regimes. The article concludes that although an argument can be advanced in favour of a more proactive workplace drug testing regime for all Australian medical practitioners, the implementation of such a regime would be costly and complicated. As a result, it should only apply to practitioners assessed as working in "high-risk" roles.

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“Dealing with the Drink”: A Case for Reviewing Gradual Regulation of Teenagers’ Access to Alcohol – Brendan Walker-Munro

Alcohol has long been a part of the social fabric of Australian culture – a fact almost irreconcilable with the finding that alcohol has been the causal factor in 5% of deaths and hospitalisations over the past decade. Although some links exist between the availability of alcohol and density of supply, the findings are not as determinative as one would hope. That reform is necessary in this area has been universally accepted by scholars, but how is it best to achieve this in a political system that favours liberalisation and deregulation, and an industry that fights against anything that would reduce their market share? This article proposes a gradual legalisation of alcohol consumption, backed by parental supervision and education, that balances individual autonomy and development into adulthood against the risks of rapid overexposure to alcohol. 415

Red Bull: Does It Give You Wings or Cardiac Disturbances? Modifying the Law Regarding Energy Drinks in Australia – Marilyn Bromberg and Justine Howard

People consume vast quantities of energy drinks worldwide. Yet, energy drinks may cause serious health problems when consumed excessively. Currently, people of any age in Australia can easily purchase energy drinks from any retailer who sells them, including bars, grocery stores, convenience stores and online stores. This article explains what is meant by the term “energy drinks” and details their health repercussions. It discusses the marketing and legal aspects of energy drinks, including the limitations of current energy drink legislation, and argues that Australian governments should regulate the licensing and sale of energy drinks similarly to how they regulate alcohol. This could significantly decrease the ability and desire of minors to obtain and consume energy drinks and compel those who distribute energy drinks to abide by strict regulations. 429

Zolpidem, Complex Sleep-Related Behaviour and Volition – Marilyn McMahon

A commonly prescribed hypnotic, Zolpidem, has been linked to accidental death, driving offences and a very uncommon legal defence – automatism. The deaths and prima facie criminal behaviour that have triggered legal concern and considerable publicity have occurred while the person was in a sleep-like state and apparently acting involuntarily after ingesting the drug. Australian courts have had a mixed response to these claims, and have closely examined the expert evidence that is essential to establishing the link between the conduct and the medication. Accepting that a connection has been established, in 2014 a Victorian Coroner suggested that guidelines issued in Australia should reduce recommended dosages of Zolpidem and increase warnings about adverse effects. However, forensic issues associated with unpredictable, complex sleep-related behaviour triggered by Zolpidem will not be resolved entirely by these changes. Exploration of the legal implications of this conduct is essential as the issue is likely to be of continuing and particular significance in Australia, where reports of adverse effects associated with this hypnotic have been more frequent than in other countries. 451

Judicial Recognition of PTSD in Crime Victims: A Review of How Much Credence Australian Courts Give to Crime-Induced PTSD – Paul McGorrery

The criminal justice system often finds itself concerned with what was happening inside someone’s mind – what they were thinking, what they were feeling, what they intended. That investigation into people’s minds, however, seems to be disproportionately more concerned with what is happening in defendants’ minds (their credibility, culpability and dangerousness) than it is with victims’ minds (the harm done). This is concerning given that one in five victims of violent crime and one in two victims of rape suffer from post-traumatic stress disorder (PTSD). This research reviews 139 reported criminal law judgments around Australia that mentioned PTSD in the 12-month period between

1 November 2014 and 31 October 2015. Of those 139 cases, it was in only 28 cases that a court's mention of PTSD had to do with whether the victim had PTSD; and of these, it was in only 11 that the victim's potential diagnosis of PTSD was somewhat or very relevant to the court's reasoning. This article suggests that victim PTSD should take a more prominent role in decision-making in the criminal justice system. 474

Collision or Collusion? Homicides Staged as Car Accidents – Claire Ferguson

A staged crime scene involves deliberate alteration of evidence by the offender to simulate events that did not occur for the purpose of misleading authorities. Staging has received little attention in the medical, legal and criminology literature, and discussions of staged car accidents are almost non-existent – bar a few case studies, no literature exists. The study examined 16 homicides staged as car accidents. The descriptive analysis examined common staging behaviours, and victim, offender and offence characteristics. Findings indicate staged car accidents present differently than true accidents. They often involve single vehicle, slow speed, downhill scenes, with middle-aged, female victims. Physical damage to vehicles is usually minimal, except for fire damage. Common offender behaviours include transporting the body to a vehicle, mutilation of the body, arson, and clean up. The results suggest these efforts are often unsophisticated and potentially identifiable to investigators and physicians. 489

Name Suppression Practices of New Zealand's Health Practitioners Disciplinary Tribunal 2004-2014 – Kate Diesfeld, Lois J Surgenor, Michael Ip and Kate Kersey

Permanent name suppression decisions related to health practitioner disciplinary proceedings can result in debate across various interest groups, including practitioners, the public, the media and complainants themselves. However, there has been no analysis of name suppression patterns, principles and practices in New Zealand since the 2004 legislative reforms under the *Health Practitioners Competence Assurance Act 2003* (NZ) provided for the combined regulation of 21 health professions and established the Health Practitioners Disciplinary Tribunal (HPDT) to hear and determine charges relating to those professions. This article reviews health practitioner name suppression debates within New Zealand in light of an exploratory descriptive analysis that was undertaken of 288 published decisions of the HPDT from 2004 to 2014. The study revealed that just under one-half of all cases involved a permanent name suppression application; amongst these, just over one-third were approved. Grounds cited for approving or declining name suppression varied and generally reflected established case law regarding naming principles and the Act's intent. While the public interest dominated as the most frequently cited reason to decline name suppression, the most frequent justification for granting name suppression was the health and wellbeing of various individuals. The findings have relevance for understanding current trends in name suppression, and whether there are changing practices or differences adopted between health practitioner groups. 500

BOOK REVIEW

Lecretia's Choice: A Story of Love, Death and the Law by Matt Vickers – Reviewed by Ian Freckelton QC 502