FAMILY LAW CHILDREN MEDICALPROCEDURE Applicant parents seek authorisation for a special medicalprocedure proposed treatment is a laparoscopic partial hysterectomy where the child does not have the capacity to consent tothe proposedmedical procedure where the proposed medical procedure is recommendedand supported by the medical practitionersinvolved in the childs care satisfied that it is in the childs best interests to authorisethe proposed treatment. Family Law Act 1975 (Cth) s 67ZC FamilyLaw Rules 2004 (Cth) Gillick v West Norfolk and Wisbech AreaHealth Authority [1985] UKHL 7; [1986] AC 112 Re Alex: Hormonal Treatment for GenderIdentity Dysphoria [2004] FamCA 297; (2004) FLC 93-175 Re Angela (Special MedicalProcedure) [2010] FamCA 98 Secretary, Department of Health andCommunity Services v JWB and SMB [1992] HCA 15; (1992) FLC 92-293 APPLICANTS: The Mother and the Father Independent Childrens Lawyer File No: By Court Order File Number issuppressed DATE DELIVERED: 23 October 2014 JUDGMENT OF: Macmillan J HEARING DATE: 29 September 2014 REPRESENTATION By Court Order the names of counsel and solicitors have beensuppressed ORDERS IT IS ORDERED THAT Thesurgical removal of Ediths uterus is hereby authorised by theCourt. Tothe extent that it is necessary, the father and the mother are hereby authorisedto consent to the removal of Ediths uteruson her behalf. Theapplicants Amended Initiating Application filed 28 August 2014 beotherwise dismissed and the matter be removed from thelist of cases awaitinghearing. IT IS NOTED that publication of this judgmentby this Court under the pseudonym Re: Edith has been approved bythe Chief Justice pursuant to s 121(9)(g) of the Family Law Act 1975(Cth). FAMILY COURT OF AUSTRALIA File No: By Court Order File Number issuppressed The Mother and the Father Applicants And Independent Childrens Lawyer REASONS FOR JUDGMENT INTRODUCTION Edithwas born in 1997 and is now 17 years of age. Edith, who has been assessed ashaving the mental age and IQ of a five year old,requires full time care andassistance. Edithwas born with Ataxia Telangiectasia, which is a rare neurological disease. As adirect result of having Ataxia Telangiectasia,Edith has a severe intellectualdisability, ataxic cerebral palsy, a sensory processing disorder and herbehaviour is challenging.She also has an immune deficiency which has resultedin her having recurrent infections and, in particular, ear infections whichhavecaused hearing impairment and behavioural changes. Dr

H, Edithspaediatrician, gave evidence that there was no prospectof any improvement inEdiths long-term prognosis. Edithsfather is 46 years of age and works full time as a skilled tradesman.Ediths mother, who is 44 years of age,is Ediths full time carer. Edithsparents were married in 1992. They have two other adult children: A, who is 21years of age and has just completeda university degree, and Y, who is 19 yearsof age and is a full time university student. They both live at home with Edithandthe mother and father, who are the applicants in these proceedings. AlthoughEdiths mother is her primary carer, the mother says that their wholefamily loves Edith and is involved in and committedto her ongoing care andsupport. It is clearly the case, as deposed to by the mother, that Edithscare presents enormous day-to-daychallenges mentally, physically andemotionally for both Edith and her family. In her affidavit sworn and filed on28 August 2014the mother describes various aspects of Ediths life andthe care that she requires, as follows: Edith cannotdress herself, bathe herself, brush her hair, clean her teeth or eat withoutfull assistance. Morning and eveningbaths and dressing are a physicalbattle [and] Edith often lashes out violently; Edith can onlyeat smooth foods and regurgitates any foods she does not know or like; Edith is bothbladder and bowel incontinent, must wear a nappy and requires full assistancewith changing her nappies; Edith has onlylimited communication skills and will only speak when she is in afamiliar environment. Edith does notexpress verbally if she is experiencing pain or distress and may instead becomevery quiet, irritable or angry, sometimesbanging objects or chewing on herfingers at such times; Edith suffersfrom extreme anxiety and is distressed by things like loud noises, crowds,thunder, strangers and anything unfamiliar; Edith regularlyself-mutilates, which includes biting, rubbing and picking at her body, oftenbreaking the skin; and Edith cannotstand foreign objects on her body and will also pick at them. Herself-mutilation is relentless. Edithbegan menstruating when she was 12 years of age. It is the impact ofEdiths menses and the detrimental effect that thishas had on her lifewhich has ultimately led her parents, based upon the recommendations ofEdiths various medical practitioners,to seek authorisation from thisCourt for Edith to undergo a laparoscopic partial hysterectomy. Edithsparents seek orders in the following terms: that it isdeclared that the removal of Ediths uterus is in her best interests; that the removalof

Ediths uterus is authorised; and that to theextent necessary the mother and father are authorised to consent to the removalof Ediths uterus on her behalf. EVIDENCE Theapplicants relied upon the following documents in support of theirapplication: their AmendedInitiating Application filed 28 August 2014; themothers affidavit sworn and filed 28 August 2014; thefathers affidavit sworn and filed 28 August 2014; the affidavit ofDr D sworn and filed 28 August 2014; the affidavit ofDr H sworn 22 August 2014 and filed 28 August 2014; the affidavit ofMr C sworn and filed 28 August 2014; the affidavit ofMs S sworn 8 September 2014 and filed 11 September 2014; the affidavit ofDr W sworn 11 September 2014 and filed 12 September 2014; and theapplicants outline of case document dated 22 September2014. TheIndependent Childrens Lawyer, in addition to the affidavit materialrelied upon by the applicants as above, also reliedupon the following furthermaterial: themothers first affidavit sworn 6 August 2014 and filed 7 August 2014; themothers second affidavit sworn 6 August 2014 and filed 7 August2014; the affidavit ofDr H sworn 4 September 2014 and filed 8 September 2014; the affidavit ofDr D sworn 3 September 2014 and filed 8 September 2014; and the IndependentChildrens Lawyers summary of argument filed 26 September 2014. Themother gave brief oral evidence in relation to some incidents that have occurredsince she filed her affidavit of evidence-in-chief.The mother was also brieflycross-examined. I found the mother to be a careful and thoughtful witness andher love and concern forEdith was evident from her evidence. Therewas limited cross-examination of the mother and both Dr H and Dr W. Dr H and DrW gave their evidence at the same time and wereable to comment on eachothers evidence. The evidence they gave was cogent and considered.Although there were a number oflimited issues about which their evidencediffered, this was, in my view, a reflection of their particular areas ofexpertise andspeciality rather than a question of credit. The main issue aboutwhich they disagreed was whether or not Edith might remove anyintrauterinedevice (IUD) that might be inserted as an alternative to the proposed removal ofher uterus. Although Dr W thought itwas unlikely that Edith would be able toremove such a device herself, Dr H, who is the paediatrician who has treatedEdith for mostof her life and has considerable experience of her behaviour,thought it was a possibility that she could remove the device. It isnotnecessary to choose the evidence of either of these expert witnesses over theother

for the purposes of the decision I must make.It is suffice to say thatneither rules out the possibility of Edith removing the IUD herself. Althoughthe relevant government agency was given notice of the proceedings by theIndependent Childrens Lawyer pursuant tothe chambers orders made byRegistrar Field on 7 August 2014, was served with the affidavit material reliedupon by the applicantsand the Independent Childrens Lawyer, and waspresent in Court both at the mention of the matter before me on 14 August 2014and at the hearing on 29 September 2014, the agency did not seek to eitherintervene in the proceedings or appear as amicus curiae. RELEVANT LEGAL PRINCIPLES Pursuantto s 61C(1) of the Family Law Act 1975 (Cth) (the Act)each of the parents of a child under the age of 18 has parentalresponsibility for that child. Parental responsibility is definedas allof the duties, powers, responsibilities and authority which, by law, parentshave in relation to children (s 61B). In most circumstances, decisions inrelation to a childs health and medical treatment would be theresponsibility of the parentor parents of a child and a normal exercise oftheir parental responsibility. There are, however, some qualifications. InGillick v West Norfolk and Wisbech Area Health Authority [1985] UKHL 7; [1986] AC 112(Gillick), Lord Scarman said, in relation to what is nowdescribed as Gillick competence, at 188 to 189 asfollows: In the light of the foregoing I would hold that as a matter of law the parentalright to determine whether or not their minor childbelow the age of 16 willhave medical treatment terminates if and when the child achieves a sufficientunderstanding and intelligenceto enable him or her to understand fully what isproposed. It will be a question of fact whether a child seeking advice hassufficientunderstanding of what is involved to give a consent valid in law.Until the child achieves the capacity to consent, the parentalright to make thedecision continues save only in exceptional circumstances. Iam satisfied that in this case Edith does not have and is never going to havethe capacity to give consent to the proposed medicalprocedure. However,although the parents in this case have parental responsibility for Edith, thatdoes not mean that the applicantsin this case can authorise the proposedremoval of Ediths uterus. InSecretary, Department of Health and Community Services v JWB and SMB[1992] HCA 15; (1992) FLC 92-293 (Marions case) the HighCourt (per Mason CJ, Dawson, Toohey and Gaudron JJ) said at [79180] asfollows: ... But first it is necessary to make clear that, in speaking of

sterilisationin this context, we are not referring to sterilisationwhich is a by-product ofsurgery appropriately carried out to treat some malfunction or disease. Wehesitate to use the expressionstherapeutic andnon-therapeutic, because of their uncertainty. But it is necessaryto make the distinction,however unclear the dividing line may be. As a starting point, sterilisation requires invasive, irreversible and majorsurgery. But so do, for example, an appendectomy andsome cosmetic surgery, bothof which, in our opinion, come within the ordinary scope of a parent to consentto. However, other factorsexist which have the combined effect of marking outthe decision to authorise sterilisation as a special case. Court authorisationis required, first, because of the significant risk of making the wrongdecision, either as to a childs present or futurecapacity to consent orabout what are the best interests of a child who cannot consent, and secondly,because the consequences ofa wrong decision are particularlygrave. Theplurality, identifying the factors that contribute to the risk of a wrongdecision being made at [79181], referred to the factthat [t]he decisionby a parent that an intellectually disabled child be sterilised may involve notonly the interests ofthe child, but also the independent and possiblyconflicting (though legitimate) interests of the parents and other familymembers.There is no doubt that caring for a seriously handicapped child adds asignificant burden to the ordinarily demanding task of caringforchildren. However, the plurality also said that [s]ubjectto the overriding criterion of the childs welfare, the interests ofotherfamily members, particularly primary care-givers, are relevant to acourts decision whether to authorise sterilisation.However, courtinvolvement ensures, in the case of conflict, that the childs interestsprevail. InRe Alex: Hormonal Treatment for Gender Identity Dysphoria [2004] FamCA 297; (2004) FLC 93-175,Nicholson CJ, summarising what the High Court had said in Marionscase, said at [153] as follows: Marions case involved an application for the sterilisation of a14-year-old teenager with a severe intellectual disability for the purposeofpreventing pregnancy and menstruation with its psychological andbehavioural consequences. The gravamen of the decisionwas that if achild or young person cannot consent her/himself to a medical procedure,parental consent (which for present purposesmay be equated with that of aguardian) is ineffective where the proposed intervention is: invasive,permanent and irreversible; and not for

thepurpose of curing a malfunction or disease. Inthis case, as it was in the case of Re Angela (Special Medical Procedure) [2010] FamCA 98 (Re Angela), sterilisation is aconsequence rather than the purpose of the proposed medical procedure. In ReAngela, Cronin J made the point that it was a fine linebetween the decision being one falling within the bounds of normal parentalresponsibility and one that, having regard to the decision in Marionscase, requires this Courts authorisation. His Honourscomments are apposite in this case. The High Court in Marions casedistinguished between sterilisation for that specific purpose and sterilisationas a by-product of surgery appropriately carriedout to treat somemalfunction or disease. The High Court, although indicating thatit was reluctant to do so, also distinguished in that context betweentherapeutic and non-therapeutic. Whilstthe proposed medical procedure in this case may not be, strictly speaking,required to treat some malfunction or diseasesuffered byEdith, it is arguably necessary for therapeutic reasons, in the moregeneral sense of the meaning of that word. The reasons for the treatmentinEdiths case are both physiological and psychological, as well as inrelation to her general welfare and quality of life.Although it was not thesubject of argument before me and the matter proceeded on the basis that thisCourts authorisationwas required for the proposed treatment, it isindeed a fine line as to whether in circumstances such as in this case thedecisionshould be one which falls within the bounds of parental responsibilityor is one that requires the authorisation of this Court. Thenecessity to seekCourt authorisation, both because of the stress to Ediths parents and thecost associated with legal proceedings(although I note that in this case theapplicants were represented on a pro bono basis at the hearing), will almostcertainly addto the many challenges associated with Ediths care. Althoughsterilisation is a consequence rather than the intended purpose of the proposedmedical procedure in this case, that procedureis invasive, permanent andirreversible and not as described in Marions case for the purposeof curing a malfunction or disease. Having regard to the decision of the HighCourt in Marions case it is in those circumstances a medicalprocedure which requires this Courts authorisation. InMarions case, the High Court held that the welfarejurisdiction conferred upon this Court was akin to the parens patriaejurisdiction (at [79184]) and that this Court had the jurisdiction to authorisemedical procedures which did not fall

withinthe ordinary scope ofparental power to consent to medical treatment (at [79166]). Followingthe decision in Marions case, in 1995 the Act wasamended to include s 67ZC which provides as follows: Orders relating to welfare of children (1) In addition to the jurisdiction that a court has under this Part in relationto children, the court also has jurisdiction tomake orders relating to thewelfare of children. Note: Division 4 of Part XIIIAA (International protection of children) mayaffect the jurisdiction of a court to make an order relating to the welfare of achild. (2) In deciding whether to make an order under subsection (1) in relation to achild, a court must regard the best interests of thechild as the paramountconsideration. Note: Sections 60CB and 60CG deal with how a court determines a childsbest interests. Itis this section which confers the jurisdiction upon this Court to make theorders sought by the parents in this case and requiresthe Court, in consideringsuch applications, to regard the best interests of the child the subject of theapplication as the paramountconsideration. Rule4.09(1) of the Family Law Rules 2004 (Cth) provides that evidence must begiven to satisfy the Court that the proposed medical procedure is in the bestinterests of thechild. Pursuant to rule 4.09(2) that evidence must includeevidence from a medical, psychological or other relevant expert witness thatestablishes the following: (a) the exactnature and purpose of the proposed medical procedure; (b) theparticular condition of the child for which the procedure is required; (c) the likelylong-term physical, social and psychological effects on thechild: i) if the procedure is carried out; and ii) if the procedure is not carried out; (d) the natureand degree of any risk to the child from the procedure; (e) ifalternative and less invasive treatment is available -- the reason the procedureis recommended instead of the alternativetreatments; (f) that theprocedure is necessary for the welfare of the child; (g) if thechild is capable of making an informed decision about the procedure -- whetherthe child agrees to the procedure; (h) if thechild is incapable of making an informed decision about the procedure -- thatthe child: i) is currently incapable of making an informed decision; and ii) is unlikely to develop sufficiently to be able to make an informeddecision within the time in which the procedure should be carriedout, or withinthe foreseeable future; (i) whether thechilds parents or carer agree to the procedure. EDITHS HEALTH Edithhas multiple health issues and her health is generally poor. Her medical historyis set out in some detail in the mothersaffidavit sworn 28 August

2014.That evidence is confirmed by the evidence of her various medical practitioners,in particular theevidence of Dr H, who has been treating Edith since she wasapproximately five weeks old, and Mr C, her ENT Surgeon who has beentreatingher for 10 years. Ediths medical history, as summarised by the mother inher affidavit sworn and filed 28 August2014, and commencing from the year ofher birth is as follows: In 1997, [Edith]had multiple admissions to the [Z] and [R] Hospitals in connection withpneumonia and an ear infection; Between 1998 and2002, [Edith] had multiple admissions to the [Z] and [R] Hospitals in relationto a number of infections. She underwentvarious tests and treatments, includingMRI scans, x-rays, CT scans, immunoglobin and grommets; In 2003, [Edith]had 13 admissions to the [R] Hospital for immunoglobin and infuse a portinsertion; Between 2004 and2008, [Edith] had multiple admissions to the [Z] and [R] Hospital[s] fortreatment of infections and to undergo mastoidectomies.She underwent numeroustests and scans and underwent immunoglobin and infuse a port removal andreplacement[;] In or around2006, when she was approximately 9 years of age, [Edith] [Edith] underwent aTonsillectomy and an Adenoidectomy; In or around2008, when she was approximately 11 years of age, [Edith] underwent a removal ofreactive lymph nodes; In 2009, [Edith]had multiple admissions to the [R] Hospital for dental procedures; Between 2013 and2014, [Edith] had multiple admissions to the [Z] and [R] Hospitals forinfections and dental procedures; On 19 August2014, [Edith] underwent her fourth mastoidectomy, which is an ear relatedsurgery whereby the mastoid bone behind theear is drilled out. [Edith] has hadboth of her ear drums repaired with muscle grafts; At the same timeon 19 August 2014, [Edith] underwent a biopsy for suspected pre-cancerous cellson her vulva. Themothers evidence, which I accept, is that Edith has had to date 84hospital admissions and 49 general anaesthetics forvarious procedures,surgeries and scans, including IV insertions, central line insertions, X-rays,CT scans and MRI scans, echocardiograms,ECGs, EEGs, immunetherapy and grommets. All of Ediths dental treatment, including x-raysand tooth/gum examinations,is required to be carried out under a generalanaesthetic. Thislong history of medical care and treatment, notwithstanding the necessity forthat treatment, has had a significant impact uponEdith. Edith does not havethe capacity to understand either the reason or need for the treatment she isreceiving or

what is infact happening to her during that treatment and,according to her mother and those caring for her, Edith has become increasinglyfrightened and confused. Themother describes Edith as being unable to tolerate anyone other than herselftouching her and, even then, only on rare occasions.The mother deposes thatEdith is extremely averse to medical and nursing staff or her teachers touchingher. Ms S, who has providednursing care to Edith since she was one year old,deposed that Edith has proven to be one of our most challenging patientsto nurse. When [Edith] is approached by staff for any procedure she becomeshighly distressed and lashes out with her hands and criesand screams. Thereason Edith has had so many general anaesthetics is because that is the onlyway in which any treatment can be administered toher. Dr Hs evidence isthat Edith is unable to tolerate any medication given orally or byinjection and that[a]ll medication has to be administered throughan intravenous line or infuser port (this had to be removed due toinfection). The mother gave some examples of the difficulties associatedwith administering medication to Edith and the problems that have beenassociated with the various methods that have been used, as follows: Edithsfirst infuse-a-port was inserted when she was approximately six years of age andhad to be removed and replaced whenshe was 10 years of age due toinfection. The secondinfuse-a-port was removed when she was 12 years of age due to infection transfercaused by Edith picking at the site, asa result of which she developed aserious Strep/MRSA infection. Another central line could not be inserted due tothe presence ofinfection in her bloodstream. For the nextthree to four years Edith was placed under anaesthetic for monthly infusions ofIntragram. Between 2001 and2004 the father and mother trialled an arrangement whereby they would administerEdiths immunoglobin via sub-cutaneousinfusions at home three times eachweek because staff at the R Hospital were unable to obtain access via an IVcatheter due to theEdiths distress, anxiety and her physicalresistance. In 2005 aHospital in the Home nurse visited the home to access Ediths centralline, as a result of which Edith became so anxiousthat she ripped out theaccess needle, causing it to snap leaving remnants in the central line. Theremnants of the needle had tobe removed under a general anaesthetic. In or about2006, whilst a patient at the Z Hospital, Edith picked at her central line untilit became unconnected to her infuse-a-portresulting in a backflow of arterialblood flowing out of that port. THE

PROPOSED TREATMENT Itis proposed that a laparoscopic partial hysterectomy, involving removal of theuterus but with conservation of the ovaries andthe fallopian tubes, beperformed by Dr W. Dr W, an obstetrician and gynaecologist who has known andtreated Edith since 2008, describesthis procedure as a relativelystraightforward surgical procedure involving a few days in hospital. [Edith]would only havea few small abdominal incisions which would be difficult tounpick and the likelihood of long term consequences is minimal as thisis a wellrecognised procedure and in the hands of an experienced surgeon has little or nolong term morbidity. InJuly 2014 the applicants sought an opinion from Dr D, a gynaecologist in privatepractice, in relation to the management of Edithsmenses and the variousoptions for treatment including the proposed hysterectomy and observed changesto her vulva. Dr D was alsorequested by the Independent Childrens Lawyerto respond to specific questions addressed to her by the IndependentChildrensLawyer. Dr Ds evidence with respect to the proposedsurgery was that Edith would be in hospital somewhere between 24 and72 hoursunless there was some unexpected pathology found at the time of the surgery. Itwas her opinion, with respect to possibleeffects of the proposed treatment,that: The only real main potential long term effect can be a slightly increased riskof having problems with a vagina vault prolapse manyyears hence. There is alsoa small risk of the development of pelvic adhesions. If [Edith] developed pelvicadhesions in most casesshe would not need further surgery unless the adhesionswere of a major nature. There is a small risk that she might need an admissionand during which she was given intravenous fluids and had nil by mouth until herbowel went back to functioning normally. WHY THE PROPOSED TREATMENT IS REQUIRED Theprimary purpose of the proposed procedure in this case is to permanentlysuppress Ediths menstrual cycle. AlthoughEdith has now been menstruating for some five years, both her mother and Dr Hhave said that she has no understanding ofwhat is happening to her and why itkeeps occurring. The mother gave evidence about the techniques she had employedto explain menstruationto Edith but that, as both the mother and Dr H said, itwas beyond Ediths level of comprehension. Dr Hs evidence wasthatEdith had no concept of memory at all and would not remember menstruating fromcycle to cycle. Themothers evidence is that Edith, most likely because of her medicalhistory and the numerous admissions and

procedures shehas had, associates bloodwith pain and becomes extremely distressed when she menstruates. As a result ofthis fear and her reactionto the blood she self-mutilates in an attempt to makethe blood stop or go away. The mother described Edith putting her fingers insideher vagina, causing physical damage to herself, and constantly scratching at hervulva. Edith also transfers menstrual blood to otherparts of her body. Themother says that Edith recently had a permanent discharge coming from her rightear, which she also pickedat, and that there was a cross-transfer between herear and her vulva. Dr H also gave evidence about Edith being at risk ofinfectionas a result of her sticking her finger in her anus and then in hervagina, which he himself had witnessed her doing on one occasion. Priorto the commencement of her menses Edith was bowel continent and partiallybladder continent. However, since Edith started menstruatingshe has become bothbowel and bladder incontinent and must wear a nappy at all times. The mothergave evidence that Edith was initiallyincontinent only during her menses andwould then regain continence a few days after her period had ceased, but that itgraduallytook longer and longer to regain continence until there was nodistinction between when Edith had her menses and when she did not.Themothers evidence was that eventually Edith did not even realise when shewas wetting herself so she and the father, togetherwith Ediths school,made the decision to have her wear nappies full-time. The mother described insome detail the attemptsthat she has made with the guidance of Edithsmedical practitioners and school to address Ediths incontinence. Sheexplained that Edith likes routine and any attempt to modify her behaviour isbased upon establishing a regular pattern and routine,but that that is notpossible whilst Edith is menstruating because any attempt to introduce such aroutine or pattern of behaviouris interrupted by each menstrual cycle. Thefact that Edith is now both bowel and bladder incontinent has significantramifications for her future prospects. Once Edith turns18 she will be requiredto leave her current school. Although Edith will continue to live with herparents, they propose findingan adult placement in an appropriate care facilityfor Edith however their choices will be governed by whether or not she iscontinent.The mothers evidence, which was not the subject of anychallenge, was that centres for continent adults have more fundingandprovide better opportunities for social interaction and outings. There is alsothe

opportunity to participate in paid work withthe assistance of carers andaids, such as addressing envelopes and folding pamphlets. The centres forincontinent adults are muchmore restrictive. DrD, who the applicants consulted in July 2014 in relation to the management ofEdiths periods, has diagnosed Edith as havingsignificant chronicinflammatory changes of her vulva and a difficult form of Candida to treat aswell as normal Candida.These vulval changes are very rare in a young woman of[Ediths] age. They come because of problems of chronicirritation. In addition to the problem caused by Edith pickingand pulling at her vulva, Dr D also said that Edith being in nappies isnot good for vulval tissue as it is intermittently but regularly in contact withboth urine and faeces. She went on to say that [c]hronicirritation of the vulva may lead to the development of pre cancerous changes andlong termcancer. Although both Dr H and Dr W said that they couldnot say that keratosis would not develop into cancer, they both opined that itwasunlikely but that it would be prudent to address the problem. Edithhas, since December 2013, had a number of seizures shortly before the start ofher menstrual cycle. Dr Hs evidence isthat there is a strong correlationbetween these seizures and Ediths menses whether physiological or as aresult of the anxietycaused by her menses. There is also no evidence of anyother physiological cause of the seizures, such as a brain tumour, althoughhedid concede that, given Ediths particular circumstances, it was difficultto investigate the causes. The mother describeda number of these seizures inher affidavit material and gave oral evidence of Ediths most recentseizure, which had occurredon the morning of the weekend prior to the finalhearing. On this occasion, the mother found Edith lying on the bathroom floor,consciousbut drowsy. Edith on this occasion, and as she had on the otheroccasions when she has had seizures, was vomiting and had had a bowelmotion.The mother said Edith then slept for a further four hours despite having onlyjust woken up, and that Ediths menstrualcycle commenced that evening. Although to date, apart from the immediate effects of these seizures, there havebeen no more seriousconsequences, there is a risk that Edith may be injuredduring one of these seizures. Apartfrom the medical issues, Ediths menses and the level of anxiety it causesher has a significant impact upon Edith andher general wellbeing both at thetime she is menstruating and generally. That level of anxiety is directlyrelated to the otherissues both physical and medical that Edith faces and

whichshe and her family must deal with. ALTERNATIVE TREATMENTS Whilstthere are other treatments available, the consensus of opinion of the variousmedical experts in this case is that they hadbeen tried but were unsuccessful,were contraindicated because of Ediths particular circumstances, or mightnot ultimatelyachieve the intended aim of preventing menstruation. Thosealternative procedures or treatments include the following: The insertion ofan IUD into her uterus. Whilst there was some dispute as to whether Edith, whodoes not tolerate any foreign objectsbeing inside her body, might be able toremove the IUD herself, any IUD would in any event need to be replaced withinthree to fiveyears even if Edith had not already removed it herself. This, aswell as the initial insertion, would need to be performed undergeneralanaesthetic. The other issue with an IUD is that it would not necessarilycompletely suppress Ediths menstrual cycleand that patients can continueto have significant spotting or, even in some instances, heavy bleeding. Dr Wgave evidence that only50 per cent of patients do not menstruate at all whilstusing an IUD. The insertion ofan Implanon into the subcutaneous tissue of her arm. This would similarlyrequire a general anaesthetic for its insertionand for its replacement everycouple of years. According to Dr D, these implants quite commonly causeirritation at the sight ofthe implant. Given Ediths intolerance offoreign objects and sensory processing disorder it is considered highly likelythatshe would scratch it out. Further, given the problems that Edith has withmaintaining hygiene, this could lead to infection as haspreviously occurred. DrD also deposed that as an Implanon causes suppression of ovarian function itwould pre-dispose Edith to osteoporosisand cardiac disease long term. This riskwould also be greater in Ediths case because of her immune deficiency. DrW alsogave evidence that the implant was unreliable in 80 per cent of caseswith those patients having intermittent bleeding from time-to-time,and thatonly in approximately 20 per cent of cases did it cause a patientsmenstruation to cease completely. Dr W also saidthe effect of the implant couldvary from implant to implant. A Depo-Proverainjection administered three monthly by intramuscular injection. InEdiths, case this would again require ageneral anaesthetic every threemonths. Depo-Provera would similarly increase Ediths risk of bothosteoporosis and cardiacdisease. It was Dr Ws evidence that there was noguarantee that Depo-Provera would totally suppress Ediths menstrualcycleand that the bleeding

could take a year or longer to stop, assuming it worked atall. EndometrialAblation, where the lining of the uterus is burnt off. Although Dr W identifiedthis as another option, he also said thatit was not guaranteed to prevent Edithhaving her menses. It was his evidence that menstruation continues inapproximately 20 percent of cases where patients have undergone thisprocedure. DISCUSSION Edithstreating medical practitioners are united in their view that Edith should have alaparoscopic partial hysterectomy.Her parents agree and seek that the treatmentbe authorised by this Court. Both Dr H and Dr W gave evidence that they hadconsideredall the other options and that the removal of Ediths uteruswas the preferred option. Dr Ds evidence was consistentwith the evidenceof Dr H and Dr W. Iam satisfied that in all of the circumstances the proposed treatment is inEdiths best interests. Whilst clearly Edithsmonthly cycles add tothe challenges her family face in caring for her, I am satisfied that thisapplication is not motivated bytheir needs but by their concern forEdiths welfare. The love the applicant parents have for Edith, theircommitment to hercare, and the important role she plays in their livesnotwithstanding the challenges that that involves is clear from the evidenceinthis case. By the standard of what most parents must do their task is enormous.Whilst the total and permanent suppression ofEdiths menstrual cycle willhopefully ease their burden, although they do not refer to it as such, it isEdiths welfarewhich is the paramount consideration. That being said itis also clearly the case that Ediths welfare is inextricably linkedwiththe welfare of the applicant parents and the family generally. Iam satisfied that the proposed treatment will not only ease the burden it placesupon Edith but is likely to be of significant benefitto Edith in terms of bothher immediate prognosis as well as her long-term prospects. Theproposed removal of Ediths uterus and consequent cessation ofmenstruation will eliminate the anxiety Edith experienceseach time she startsmenstruating which is, for her, a new and daunting experience on each occasion.I accept the mothersevidence that Edith is terrified of blood,associating it with pain, and self-mutilates during her menstruation to try andmake theblood stop or go away. The cessation of Ediths menses willeliminate her reason for her self-mutilating and prevent any furtherdamage toher vulva or any other part of her body and reduce the risk of infection she isexposed to as a result of her reactionto the menstrual blood. Whilstthere is no guarantee that as a result of the removal of Ediths uterus,and

the fact that she is no longer having aregular period, that Edith willregain her continence, I am satisfied, particularly having regard to theevidence of the mother asto Ediths need for and response to routine inher life, that Edith will almost certainly remain both bowel and bladderincontinentwhile she continues to menstruate. This has both long and short-termimplications for Edith, particularly having regard to the factthat she isalmost 18 and the options available to her once she leaves her current schoolwill depend upon whether she is continentor incontinent. Whetherthe seizures she has been having are physiologically related to the commencementof her menses each month or a result of theanxiety she now experiences as aresult of her menses, I am satisfied that it is less likely that she willcontinue to have thoseseizures if she is not menstruating and that this islikely to reduce the risk to Edith associated with those seizures. Iaccept the evidence of Ediths various treating doctors that thealternative treatments are not suitable in her case. Whilstthe proposedtreatment is invasive, it is moderately so and I am satisfied that in the longterm it is likely to be less invasivethan some of the other alternatives whichwill require Edith to undergo not just one but many more general anaesthetics. Theproposed procedure is permanent and irreversible in the sense that it will bothend her menstrual cycle but will also precludeany possibility of Edith bearinga child. Whilst Ediths sterilisation is the ultimate consequence of theprocedure, it isnot the purpose. The mother deposed to her view that there wasno realistic prospect of Edith either forming a romantic relationshipormothering children. I accept the mothers evidence which, together withthe evidence of Ediths treating medical practitionersand the nurse whohas cared for her over a period of 10 years, and in particular the evidence withrespect to Ediths sensoryprocessing disorder, leads me to conclude thatEdith would have a very limited capacity to form a relationship which might leadtoher wanting to bear a child, that she would not have any concept of whatwould be involved in having a child, and that she wouldnot have the capacity tocare for a child. Inall of the circumstances I am satisfied that, although there are risksassociated with the proposed treatment, those risks areoutweighed in this caseby the physical and psychological benefits to Edith and what is likely to be asignificant improvement inthe quality of her life both in the short andlong-term. I am satisfied that the proposed treatment is the most appropriateoptionconsidering all of the alternative

treatments and is the most likely topromote Ediths physical and emotional wellbeing. Inall of thecircumstances, having found that it is in Ediths best interests toundergo the proposed laparoscopic partial hysterectomy,I propose to accede tothe application. I certify that the preceding fifty-one (51)paragraphs are a true copy of the reasons for judgment of the Honourable JusticeMacmillandelivered 23 October 2014. Associate: Date: 23October 2014 