

DR MARISA PATERSON MLA SPEECH

23 APRIL 2021

Motion to review support and regulatory services for Assisted Reproductive Technology in the ACT

Colleagues and members of the ACT's Tenth Legislative Assembly, I give notice to move that this Assembly call on the ACT Government to review the support and regulation for Assisted Reproductive Technology patients, donors and service providers in the ACT.

Many jurisdictions across Australia have legislation and regulatory regimes that provide a framework for ART. The ACT currently does not have any such regulatory arrangement.

ART includes all fertility treatments in which either eggs, sperm or embryos are handled.

ART includes a range of fertility treatments such as Ovulation Induction, Artificial Insemination and In Vitro Fertilisation (IVF).

The first 'test tube baby', conceived through ART treatment, was born in the UK in 1978.

Since then, the number of ART procedures has risen dramatically. In 2018, there were 84,064 initiated ART cycles in Australia and New Zealand. In the five years to 2017, the number of ART procedures increased, on average, by over 10 percent each year. Latest estimates indicate that 3.1% of babies born in Australia are a result of ART treatment.

The most common, IVF, is a complex treatment, of which one cycle alone takes several months and cost thousands of dollars. The process for IVF patients includes attending consultations with one or more specialists, taking medications to allow for egg production, regular ultrasounds and blood tests, a surgical procedure to retrieve the eggs, sperm collection, insemination outside the body, embryo transfer and maybe daily pills or shots of progesterone for the first 8-10 weeks of pregnancy. Depending on the complexity of the case, the process can also involve a range of other surgical and clinical procedures.

This often comes with an acute emotional and physical strain.

Many patients require more than one round of treatment to become pregnant – if at all. Although ART and IVF can increase a women’s chance of becoming pregnant, it doesn’t work for everyone. This can cause emotional distress and heighten financial burden, as well as placing stress on relationships.

ART can also be an incredible euphoria for those who have success; and we are lucky to have these procedures and health practitioners available.

I am calling for a review of ART services and regulation in the ACT to ensure that patients – including those undergoing treatment (female and male), as well as gamete donors – receive the best possible information, care and support throughout their journey.

In other jurisdictions...

In some jurisdictions, legislation and regulation include a range of matters associated with ART.

In Victoria and South Australia an individual or couple can only access ART if it has been deemed that conception by means other than ART is unlikely, or there is risk for serious genetic effect.

Victoria’s legislation also establishes the need for clinic registration, consultations about treatment, and a Patient Review Panel – responsible for considering applicants from ethically complex issues.

NSW has legislation which governs the registration of providers, prevents commercialisation of human reproduction, and protects the interests of the person potentially born, donors and patients undergoing treatment.

In the ACT, along with some other jurisdictions, the decision to take on an ART patient is at the discretion of the service provider, with no regulated criteria for accepting patients, nor for accredited licensing or registration of ART clinics. In the absence of legislation, ART practitioners must comply with the ethical standards of governing bodies including the Fertility Society of Australia, the Reproductive Technology Accreditation Council and the National Health and Medical Research Council.

I have no doubt that our ART practitioners in the ACT apply sound judgement and due diligence when accepting an ART patient or donor, and in the provision of their services.

However, it is of benefit for patients, donors and service providers to undertake a review, in the context of comparable legislation elsewhere, and global best-practice, to ensure appropriate rigour and consistency is applied across all ART services in the ACT.

Donors

Of real concern to me is the lack of regulation in the ACT is the matter of gamete donation – that is: donations of eggs, embryos and sperm. Ethical questions arise as to whether conception should occur with the knowledge that a child will never know, or have any knowledge of, one of her or his genetic parents.

I acknowledge that this is a very complex and emotive issue, with many different opinions and perspectives. However, I am keen to ensure that this is a matter that is comprehensively researched, analysed and understood, so that the ACT has an informed and considered approach to the legislation recognising the rights of a donor conceived child to identify their biological parent or obtain information about their genetic heritage and background; should they wish to do so.

The ACT is not alone in a lack of record and recognition of gamete donation. The Northern Territory, Tasmania and Queensland also have no legislation governing the release of information to people involved in donor conception.

I call on the ACT Government to review the rights of donors to be recognised as such, and the rights of donor conceived children to have opportunity to connect with their medical and genetic history at the very least, should they wish, at an appropriate stage in life.

Support

I note that ART can be a traumatic experience for individuals and couples. Many couples spend months, years and tens of thousands of dollars trying unsuccessfully to have a child.

Regarding patient support – and this is a big one – I want to ensure that patients in the ACT feel like they have the best possible care and treatment when undergoing ART treatment.

Across Australia, there are many different patient experiences, with the level and quality of services varying considerably from clinic to clinic. Patients describe everything from:

- ‘the whole process felt like I was just on a production line’

- ‘the staff said to me “beggars can’t be choosers” – I’d never considered myself a beggar before, but that brought an additional level of shame and pain to what was already a traumatic process’.
- ‘it was a completely traumatic process. We felt just like numbers – we weren’t people at all; we were just next in line in a very expensive queue of false hope’

To:

- ‘It’s naturally a clinical and difficult process. Friendly and understanding staff seem to be vital to make people not feel like a number’
- ‘Our support team were great. We had the same nurse each time, she knew our situation and we were treated with kindness and care’.

Setting realistic expectations from the outset about the likelihood of success is paramount to patient experience. The recent establishment of the National Register of IVF Clinics goes some way towards this, whereby people can compare success rates of clinics, based on criteria pertaining to their circumstance.

Counselling also needs to occur pre, during and post treatment. Post-treatment counselling needs to address matters particularly for people who come to the end of their ART journey and face the prospect of never having children.

Men

I also want to draw attention to the need for support services and care for males involved in ART – either with a female partner or as a donor.

In a society of gendered norms where men are, typically, expected to be strong and invulnerable, I imagine many men carry a sense of responsibility to provide care to their partner who is undergoing treatment; but while also suffering emotionally themselves.

There are also men who suffer an emotional turmoil in cases where it is a male factor that prevents a couple conceiving naturally.

I want to ensure that ART services recognise the unique needs of both men and women, and are capable of providing personalised services where patients – female and male – don’t feel like they are just a paying client.

Expense

Which brings me to another point – ART is expensive. Even after Medicare rebates (and private health insurance for those who can afford it), an individual or couple is likely to be out of pocket at least \$4,000 per IVF cycle.

Lower income people in our community cannot afford to pay for ART treatment, and especially when there is no guarantee they will have success.

As part of this Motion, I call on the ACT Government to investigate funding models and explore opportunities for ART services to be available for lower income individuals and couples in our community.

Mitochondrial donation

The Federal Government has recently introduced a Bill in the Australian Parliament addressing mitochondrial donation. If passed, it will allow for the use of permitted mitochondrial donation techniques as part of the ART process across all Australian States and Territories. This will allow women whose mitochondria would otherwise predispose their potential children to severe and life-threatening mitochondrial disease, to have a biological child who would not inherit that predisposition.

In moving this Motion, I call on the ACT Government to consider the potential impact of this Bill on the ACT's legislative arrangements.

Closing statement

I know some, if not all, of our ART service providers in the ACT provide excellent patient care and services of the highest professional standards.

In bringing this Motion to the Assembly, I do so – not to in any way criticise our clinics and their staff – but to ensure that our attention is on patients, and that their emotional wellbeing – and that of donors – is the first priority in ART treatment.

I am calling on the ACT Government to review – and report by August 2022 – on the availability of ART support services, comparable regulatory arrangements in other jurisdictions, the appropriateness of the current regulatory regime in the ACT, the potential impact of the Federal Government's *Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021*, and the availability of ART for low-income earners in the ACT.

ART is a life-changing experience. It's emotionally and physically draining. It's invasive, distressing and can be a long, grief-filled process. In contrast, it can be the most life-giving, joyful experience for individuals and couples. I want to make sure

that anyone in Canberra undergoing ART treatment is provided with the best possible care, resources and patient support.

I look forward to continuing to be a part of the discussions with colleagues, stakeholders and the community, to help influence best-practice outcomes for ART support and regulation in the ACT.

Ends