

Welcome to the October 2012 edition of the AccessAustralia eNews.

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... also upcoming events and recent news articles of interest to those who have difficulties conceiving.



1. AccessAustralia contributing to infertility patient associations around the world

AccessAustralia was well represented at the recent international meeting of the International Consumer Support for Infertility (iCSI) group in Kyoto, Japan. CEO Sandra Dill and Chair David Rawlings both presented to the meeting, sharing the experience of AccessAustralia to other infertility patient organisations from around the world.

Sandra also shared her wealth of research experience in surrogacy to the Asia-Pacific Initiative on Reproduction (ASPIRE) conference. The patient session, which featured Sandra's talk, was an important chance to put the patient viewpoint in front of a conference that was primarily focussed on clinicians, scientists and those involved in the management of fertility and assisted reproductive technology treatment.



2. AccessAustralia now represented on Government ethics committee

We are proud to congratulate AccessAustralia CEO Sandra Dill on her appointment to the Federal Government's Embryo Research Licensing Committee for the 2012-2015 triennium. Her appointment was announced recently by the Federal Minister for Health, Tanya Plibersek.

Sandra will bring considerable experience to this committee, which will monitor research in this field. She will also be a voice for patients - and our members - in these discussions.



3. Emotional infertility is just as hard as physical, says new survey

More than half of the respondents to a UK survey thought that the emotional side of infertility is just as painful as the physical. While most people who have an infertility journey already know this, the fact that the emotional side of infertility is getting media coverage is an important thing.

For the full story, please read: <http://www.liverpoolecho.co.uk/liverpool-life/fashion/2012/09/12/emotional-infertility-is-just-as-hard-as-physical-says-a-new-survey-100252-31815018/>



4. Research roundup

In looking around the web this month, our eye has been caught by two particular research projects which have the capacity to bring significant benefits to infertile people around the world.

The first is a research finding from here in Australia. Scientists in Melbourne have recently found a pair of proteins that cause the death of early egg cells in the ovaries. Blocking these proteins means cells survive the effects of radiotherapy – which has massive benefits in preventing infertility caused by cancer treatments.

For the full story:

- From RedOrbit.com: <http://www.redorbit.com/news/science/1112699185/cancer-infertility-treatment-puma-noxa-092312/>
- From the Medical Daily: <http://www.medicaldaily.com/articles/12280/20120922/researchers-find-new-target-infertility-treatment-women.htm>

The second research development is from the UK, where a team from Cardiff University is investigating whether adding a protein to sperm could activate infertile human sperm into fertilising an egg. It is thought that 2,000 couples in the UK could benefit from this treatment – once it reaches this stage – but patients around the world could also benefit, including here in Australia.

Read more:

- FirstPost.com: <http://www.firstpost.com/fwire/a-protein-shot-could-help-infertile-human-sperm-465259.html>
- The Daily Telegraph: <http://www.telegraph.co.uk/news/9558398/Hope-for-thousands-of-infertile-men-from-British-discovery.html>



5. Infertility in obese women may be due to damaged eggs: US study

Obesity has long been associated with infertility as well as lower success rates with in vitro fertilization, and now researchers think they understand why: Obese women are more likely to have abnormalities in their eggs that make them impossible to fertilise.

Read more: <http://www.boston.com/dailydose/2012/09/12/infertility-obese-women-may-due-damaged-eggs-brigham-study-finds/CeqpUqhSM1r1gaDBF6DqHI/story.html>



6. The Top 10 Challenging Comments ...

In a follow-up to our last edition, this the third and final part in a series of articles about dealing with some of the more difficult comments people make to you when you're dealing with infertility. This article comes from the AccessAustralia Chair, David Rawlings, who is also the author of the book [Swimming Upstream: the struggle to conceive](#)).

In my last article, I looked at the issue of the things that people say and why they say them. Why does an innocuous comment make you want to leap over the table and rip someone's head off? Why is it that if your mother or mother-in-law imparts 'wisdom' about conception it makes you want to hire a hit squad?

I found when researching [Swimming Upstream](#) that this basically came down to two things: myths and misinformation or awkwardness. [Check out the previous two articles for more information on this].

The responses to these comments vary according to the individual, but the common theme among them is anger. Anger at what at the time appears to be great insensitivity or a lack of caring. The other common element is pain. It's that old concept of salt into the wound because that's what it can feel like at the time. The anger and pain may not just be about you, but also be about your partner. It's pretty tough to stand by and see her grapple for the words to say or see her stop in her tracks by one simple comment.

It's normal to feel that way.



But how you react will have an impact on you and those around you. You can't just explode at people who say things that are insensitive, that's not in the bounds of common politeness. If you quietly simmer over the incident or what you could have said, you'll end up with an ulcer. In most cases, you are definitely not wanting to just cut that person off from future contact but you want to manage that contact and it's pretty hard work.

In the heat of the moment, it can be very difficult to take a deep breath and give the right, calculated response. So it may help to know what other people have said in your situation or at least to know of some possible things to say or do that have worked for others.

So what can you say at the time?

Firstly, let's break it down. If you were to analyse what it was about someone's comment to you that caused a reaction in you, you would see several elements.

What you heard ... This is how you probably interpreted the comment you've just heard.

How it was probably meant ... As mentioned earlier, there are varying reasons why people try to offer you advice or ask questions. It is probably well-intentioned, but just misses the mark because it's naïve or misinformed. Generally people just don't know what it feels like, especially if they had their children without thinking about how they did it.

Your response ... How you respond to something that pushes your buttons will affect you, that person and your relationship with them. Sometimes you will handle comments and questions differently – depending on whom you're talking to, where you are and how you are feeling at the time. Your responses will probably be very different depending on whether it's your parents, a workmate or close friend you're talking with. It's almost never appropriate to fire back an angry or sarcastic response at everyone, despite how good it may feel at the time.

If you did, it would damage a valued relationship. Sometimes just saying it honestly is the best thing to come from a conversation. Many couples say they are educating their loved ones about their situation by just being honest about how they feel. It's hard to do but respects that they probably won't know how you feel unless you tell them.

These suggestions are just that – suggestions. They are not necessarily something to write on a cue card that you can drag out whenever required, neither are they guaranteed to get you out of a conversational jam. Each situation may require its own verbal two-step to ensure the outcome is what will get you through at the time. It may sound bizarre, but actually practising these situations can make it easier as they occur. And while it may seem like you're learning your lines, it will save you heaps of stress in the heat of the situation. After all, professional athletes don't practice during matches.

So, to follow on from our last article, how do you respond to the Top 10 Most Challenging Comments.

1. Just relax and I'm sure it will happen.

What the hurt, angry you may have heard: “I’m the expert on what you’re going through. It must be you causing the problem. Getting pregnant is easy; everyone does it. Just stop worrying and it will happen.”

Some possible responses:

“Well yes, we think being relaxed is the best way to be in life, but there is little or no evidence provided by science to connect relaxation and pregnancy.”

“Sadly, my wife lost her fallopian tubes in our second ectopic pregnancy. No amount of relaxation is going to fix that one.”

“If only it (your solution) were that easy!”

2. So when are you two going to have children?

What the hurt, angry you heard: “Why don’t you two hurry up? It’s about time you joined the rest of us. Why do you two want to be different? Is there something wrong with you or don’t you want children?”

Some possible responses:

Now, the responses may change according to the stage of your life that you’re in. Early in the piece, you may say, “When the time is right.” Later on you may say “we’re trying but it hasn’t happened yet.”

“Unfortunately we are having problems.”

“It’s not easy for everyone. 15%-20% of the population has trouble having babies and unfortunately we happen to be in that group.”

3. What’s the matter mate? Shooting blanks?

What the hurt, angry you heard: “Not much of man are you? Are you some kind of eunuch or something?”

Some possible responses:

“Actually I do have a problem. And you making comments like that doesn’t help me to cope with it.”

“No, but it is very offensive to hear you talk like that.”

“One day your own children might have a problem and I’m sure you wouldn’t want them to have to hear comments like that.”

4. Don't you want children?

What the hurt, angry you heard: "You must be one of those yuppie couples who think money is more important than having kids."

Some possible responses:

"There is nothing more in the world that we want. But unfortunately wanting children doesn't automatically mean that you'll end up with them."

"We have been unsuccessfully trying for several years."

"Yes we do, but sometimes you don't always get what you want. To us, you are very lucky to have your children."

5. We had a friend who tried X (where X equals adoption, IVF, having sex at precisely 3.48pm every afternoon for a week) and they got pregnant straight away.

What the hurt, angry you heard: "Try this solution. It's guaranteed to work and will be just the quick fix for you too. How silly are you for not knowing such a simple thing?"

Some possible responses:

"I think it's great that your friend was able to have their child, but like most things in life, there is rarely one answer for all."

"Unfortunately from our research we are aware that what you suggest happens only to a lucky rare few."

"We are continually reminded by our treatment team to have a balanced view about what will and what won't work."

"Even the best IVF team can't guarantee a baby."

6. (For those with secondary infertility) You should be grateful that you already have a beautiful child.

What the hurt, angry you heard: "You're just plain greedy. You've already got one child, what more do you want? There are hundreds of couples who would die to have at least one child."

Some possible responses:

"I'm sure you know how much we adore our child. Well, it's so clear to us now why we had the first one and we just want more of that feeling again."

“Yes, we’re grateful and we count our blessing every day. But there’s nothing wrong with wanting to have another child.”

“Even if we didn’t want another child, it’s pretty hard to handle little Johnny crying himself to sleep every night because he wants a baby brother or sister.”

**7. You just need to be more positive or
You just need to have more faith in God.**

What the hurt, angry you heard: “Your situation is actually your fault because your negativity or lack of faith is somehow linked to your inability to conceive.”

Some possible responses:

“Saying things like that unfortunately discounts what it is really like to have problems having a family.”

“Many things can come along to test our faith. Life is not always straightforward and bad things can and do happen in life.”

“Staying positive when you have a fertility problem is a pretty big challenge. We think we’re doing alright actually.”

8. You’re just going to have to accept that you won’t have children.

What the hurt, angry you heard: “Stop complaining and get on with your life.”

Some possible responses:

“Sadly, you might be right. But until all our options are exhausted and we’re ready to make that decision, we’re going to keep trying.”

“Yes. It can be a real struggle to keep going through all the ups and downs of this but these decisions can only be made by the two of us. At this stage we don’t even know what it is we have to accept. Whether we stop tomorrow or keep trying for another ten years is something we will work out.”

“If and when we know that we definitely can’t have children, then, and only then, we will learn to accept it.”

9. It’s alright for you’ you’re on two incomes. You’re just lucky.

What the hurt, angry you heard: “Stop your whinging. You have heaps of money and that should compensate for the fact you have no kids – what more do you want?”

Some possible responses:

“I guess coping with children must be difficult at times but it’s a bit hard to see that when it is our dearest wish to be parents.”

“I’d give it all away for one sleepless night with my child.”

“Having no children isn’t our choice.”

“I’d say we were lucky if we were able to have the one thing that we want most – children.”

10. My husband just has to look at me and I’m pregnant.

What the hurt, angry you heard: “We are some kind of ultra-fertile super-studs. You are nothing compared to me.”

Some possible responses:

“You’re just lucky. There are many people who really struggle to have children.”

Honourable mentions

As with all Top 10 lists or compilations, there are always some that miss out. Honourable mentions to these comments that just missed the cut:

“You must be having great fun trying.” (Um, no, I’m not enjoying having my sex life co-ordinated by a timetable on the fridge and a thermometer next to the bed.)

“We had terrible trouble having children – took us six months.” (Sometimes people try to ‘get alongside you’ in order to make you feel that you’re not alone. But if you’ve taken three years, it can really devalue your experience and become competitive.)

“Why do you keep trying? It’s obvious that you’re in pain.” (Continuing to follow your dream to have a child after perhaps years of pain doesn’t make sense to some people. To them, you have a problem and you can fix it easily by stopping to try to have a family.)

“You’re so lucky you haven’t got kids. Why would you bother?” (Sometimes people look at the downside of having kids – lifestyle restrictions, financial burdens – and compare it with what a childless couple has. But if you were to ask them to give up their children, there’s no way in the world they would do it.)

“You never know when a miracle is going to happen.” (This kind of comment, while well-meant, just brushes off all of your experience, emotions and pain. It isn’t as simple as this and the problem is you know that only too well).

“It will happen when you least expect it.” (This can be hard to hear when you’ve been expecting it for the past x number of years. It’s not likely to sneak up on you or appear under a rock in the garden when you’ve turned over every stone possible.)

(If you’ve moved on after unsuccessfully trying to have kids) “Why don’t you keep on trying?” (Well, the reason you’re not trying is because it’s painful, costly and possibly pointless. Coming to a decision that you will no longer pursue your dream of having kids can be a very long process. Having someone imply that you’ve given up easily really devalues the whole process you’ve just been through in coming to what is one of life’s hardest decisions. This kind of comment can also imply that trying to have a child against all odds is easy.)

“We’re not happy. Our new baby is a girl and we desperately wanted a boy. Life’s not fair!” (Not fair? You should be thankful that you’re going to be a parent.)

“We haven’t seen you guys around much.” (This may be a veiled way of asking why you’ve withdrawn from friends or family. It’s the question that’s asked without asking a question. It also reflects the misunderstanding that you can carry a potential fertility problem and continue to happily see people who have children or are expecting them. But at least they’ve given you a chance to open up a discussion with them and educate them about how you’re feeling).

“Why do you want kids? You can have mine.” (Unfortunately, some people hear this from friends who find parenting a real challenge and maybe not very rewarding. And while it may be meant as a throwaway line, it can still be very insensitive. It can also make you feel the injustice of someone being able to have kids even though they have shown that parenting skills are not their greatest assets.)

*“What about something like IVF?” (This **could** be a very helpful comment – someone has seen a possible solution and they’re offering it to you. But what this person may not know is that most people who have struggled to conceive have at least thought of just about every possible avenue to have a child.)*

“Would you like me to come around and fix up your wife for you?” (Believe it or not, but this comment can actually be a frequent one when guys get together. It’s a competitive statement that is trying to be funny. It’s not funny and never will be.)

“You know, you really shouldn’t leave having children for too long.” (They’re telling you something which may be right – you shouldn’t leave having children for too long – but what they don’t understand is that you’ve been trying for a while and you know this fact quite well. This comment also makes the general assumption that you’re in control of your fertility. If only it were that easy.)

Swimming Upstream is available online at www.swimmingupstream.com.au.



7. Antioxidants may assist infertility in older men: study

MIDDLE-AGED and older men who get enough antioxidants in their diets, through eating foods such as broccoli and tomatoes, may have better-quality sperm than men who don't get as much of the nutrients, according to a US study.

Read the full story at:

http://www.omantribune.com/index.php?page=leisure_details&id=7925&heading=Special%20Features%20in%20Details



8. Approaching life without children

The 'Approaching Life without Children' group is a social and support group of women who haven't been able to have children. The group has been meeting for ten years in Sydney and meets for lunch every two or three months, usually at Darling Harbour on a Saturday.

Those who come along are welcome to share their stories, or can just enjoy great conversations and company. Any discussions are confidential.

One member of the group described the meetings: "what a relief and how wonderful it is to meet with other women who really do understand how you are feeling. I am so grateful to have found these women that I now call my friends."

If you're in Sydney, and the group sounds like something you might enjoy, please contact the group through this email address: lwoc@access.org.au.



9. Don't forget to join us on Facebook!

Thanks to those members who've joined us on Facebook, shared their stories, asked questions and offered their comments. If you'd like to join in the conversation, we're sure there are other members who will benefit from hearing how you've addressed the issues you've faced ... along with the support of sharing your story in a safe community that understands what you're going through.

We realise that infertility can be a very personal time for some, while others enjoy being able to share their experience and learn from others. So what do you want to be able to do? Please let us know at info@access.org.au or simply post!

10. My story

The stories of our members inspire us. Dealing with infertility, treatment, adoption or moving on with life without children can be a personal journey and we thank those members who are willing to share their story as a way to help others.

“I am a 26-year-old woman experiencing something I never imagined I'd have to deal with.

After our wedding we tried for over 18 months to conceive naturally. With no success we saw our local doctor who referred us on to Queensland Fertility Group to investigate. After tests on my partner and myself it was discovered my egg reserve was not at a level for my age but that of a 48-year-old. My hormone results also indicated I was rapidly heading towards early menopause and my egg reserve would also decline with this onset in a few years. We were advised IVF was our only option to conceive.

After absorbing this shock we were shown the costs for each cycle. The first cycle was listed as costing \$9000 and every cycle thereafter costing \$8000. All costs needed to be paid in full before any treatment could begin. Medicare does assist by reimbursing around 80% which added up to \$4000 for the first cycle, \$5000 for each extra cycle. Our Private Health also covers a bit leaving us with out of pocket costs of \$3500 and \$2500.

We decided to approach our bank for a loan only to be told “we don't meet lending criteria and have lack of security for the loan”. We didn't have any property to borrow against and with my car only being 80% paid out we got knocked back at every bank and credit union I approached. Even when I showed them what Medicare reimbursed along with my Private Health cover I was told that they are unable to put that information in the application and couldn't help. Two banks and two credit unions all gave the same response.

Due to us unable to come up with the costs for treatment we had to cancel our planned cycle due to begin in August and I'm at a loss as to why no one will help us. Since then I've contacted my Local, State and National Government Departments and have asked if any Grants or Loan Schemes were in place to assist Fertility Patients and besides the Medicare rebate (*Which is reimbursed after costs are paid upfront*) there isn't anything to help people unable to get costs upfront and this surprised me.

I feel let down by our Government in lack of support for these upfront fees. I have met up with other patients in my local support group and trawled numerous online blogs and the number one issue all speak of is the upfront fees and the stress this brings with it even when working multiple jobs, properties they can borrow against and people in the mining industry earning good pays they all feel the financial pressure.

It's time to change this trend and I'm hoping getting my story out into the community will educate those unaware of who this affects and to raise awareness on Fertility Issues

Some suggestions I've come across so far include:

- Applying Medicare rebate upfront as Bulk Billing to reduce upfront out of pocket costs so treatments are affordable and in reach of all who need treatment
- Creating a payment scheme similar to the HECS set up

- Grants for extreme infertility results in patients who are in a recognised legal union
- Adopting UKs offer for couples under 36 with no children between them and in a recognised legal union to have the first treatment free
- Raising community awareness and education through media outlets on the issue

I've since started a Petition in my state of QLD and I'm hoping someone in Parliament will see that things can be better for us and will help make Positive change for us all.

Staying strong,
Catherine Odgers

Our heartfelt thanks to Catherine for sharing her story. If you'd like to do the same, please email David at news@access.org.au. We will respect your anonymity if you wish to remain anonymous.



News articles:

Treatment and infertility issues in the global news in the past month:

- How we can beat infertility, The Citizen, Tanzania
< <http://thecitizen.co.tz/editorial-analysis/19-editorial-comments/25880-how-we-can-beat-infertility.html> >
- IVF gaining popularity among villagers, Times of India, India
< <http://timesofindia.indiatimes.com/life-style/health-fitness/health/IVF-gaining-popularity-among-villagers-Expert/articleshow/16472510.cms> >
- Ethics debate opens three parent IVF technique, The Week, UK
< <http://www.theweek.co.uk/health-science/49066/ethics-debate-opens-three-parent-ivf-technique> >
- Why obese women have difficulty conceiving from IVF, Zee News, India
< http://zeenews.india.com/news/health/health-news/why-obese-women-have-difficulty-conceiving-from-ivf_18784.html >
- Frozen egg donor banks sprout in wake of new technology, Orlando Sentinel, USA
< http://articles.orlandosentinel.com/2012-09-08/health/fl-fertility-donor-eggs-20120904_1_eggs-healthy-donor-ivf-specialists >



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Your feedback

AccessA eNews is published for the members. If you have any feedback, thoughts, ideas or links you would like to see included, please send them through to David Rawlings, eNews editor at news@access.org.au.

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