

Welcome to the December 2011 edition of the Access Australia eNews.

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



1. Merry Christmas from AccessAustralia

Christmas is here again and for those who have had their dreams realised during 2011 in the birth of a longed for child, this will be a special Christmas.

For those who remain childless it can be a difficult time with so much emphasis on families and children. However, it can be an opportunity for us to begin our own traditions and celebrate our time together instead of merely surviving Christmas.

We hope your Christmas is joyful as you share it with those you love.

The team at AccessAustralia



2. Some tips on surviving Christmas

As many of you know, for infertile people who do not have a child, special family celebrations like Christmas can be painful reminders for us of the fertility and success of other people – times to be endured.

Christmas is a time for family, a time for children and a time to celebrate a special birth in history. But for infertile people, this time can be a painful reminder of a longed-for child. For those of you who have been fortunate to realise your dream of having a child this year, we hope this will be a special Christmas celebration for you. For those who are still working towards that goal on treatment, we hope that next year will bring you everything that you wish for.

Some thoughtful planning can help to reduce the sadness and increase your chances of having a peaceful and even pleasant Christmas time.

Decide to:

- Plan to see your parents or other family members a week or two beforehand so they know you care about them. This will leave you free to spend Christmas Day quietly.
- Attend a late Christmas Eve or early morning church service rather than the Family service on Christmas Day.
- If you find family gatherings too painful, make plans to spend some time with other infertile people who do not have children.
- Take time to share your feelings with your partner. Allow yourself to feel sad, deprived or depressed. Infertility is a major life crisis and you are entitled to these feelings. In sharing them you may be able to help each other through this difficult time.
- Stay in touch with other infertile friends who understand your position and may be able to offer support.
- Accept the hurt you experience because it is evidence of the love you have for the child you mourn.
- Plan to develop your own traditions and rituals to celebrate Christmas. This will give it special meaning for you, while reducing painful reminders about your infertility and childlessness.
- At Christmas you may like to give your partner a small memento to recognise their commitment to become a parent.

Decide not to:

- Shop at large shopping towns where families, children and Christmas promotions abound.
- Feel guilty about not participating in all the traditional family celebrations.
- You need to concentrate on supporting each other.
- Forget that you need each other especially during this difficult time.
- Expect others to understand your pain. Refer to it briefly and ask that they support you by respecting your choices.

For families and friends of infertile people: Your family member or friend will appreciate your understanding and support. Below are some suggestions for you to consider.

- Don't feel rejected if your family member or friend wants to spend Christmas Day alone. They love you and don't want to spoil your celebrations with their sadness. Let them know that you would like to see them but will understand if they do not feel they can attend.
- Don't feel that you need to "fix" things. You can't. Just understanding and respecting their wishes will be comforting.

AccessAustralia will have a support line available from December 24-26, if you would like to speak with someone who understands that coping with Christmas can be difficult. You can call 0419 019 690 from 9am to 7pm.

3. Thanks to members who helped out by telling their stories to the Sydney Morning Herald

We sent out an email in November, asking for members' help in telling their stories to the Sydney Morning Herald. Our heartfelt thanks for those members who did respond – two stories appeared in the SMH, which we are sharing here for you.

Heartbreak for parents with rare genetic condition

An ominous silence followed the brief first cry of Abby Baines, and then the controlled chaos of a hospital emergency response. Doctors were "basically walking up the corridor while they did CPR at the same time on our little daughter," says her father, Scott, of the first minutes of Abby's life in October 2006.

Abby's heart was destined never to support her. She had inherited myotonic dystrophy - a genetic condition that prevents normal function of muscle cells - from her mother, Naomi, who has a mild and previously undiagnosed form, and she died five weeks later in her parents' arms.



Read the full story: <http://www.smh.com.au/national/health/heartbreak-for-parents-with-rare-genetic-condition-20111107-1n3yp.html#ixzz1dAVqiQ1k>

Double bubble: doctors concerned over IVF twin births

WHEN her pregnancy scan revealed two tiny heartbeats, Melinda van Leeuwen felt mostly relief. "My first thought was, 'I'm glad it's not triplets'," said the 39-year-old, who was already the mother of a toddler.

Five previous in-vitro fertilisation (IVF) cycles - two of them involving double embryo transfer - had resulted in one son, Benjamin, conceived on the third round of treatment for Dr van Leeuwen and her husband, Graham.

Read the full story: <http://www.smh.com.au/national/health/double-bubble-doctors-concerned-over-ivf-twin-births-20111108-1n5iO.html#ixzz1dAWCzb4C>.



4. Dealing with your parents: the 'grandparents in waiting'

There is one relationship that some couples find the most stressful when they're having trouble conceiving. And that's with their parents. This article comes from the AccessAustralia chair, David Rawlings, who is also the author of the book *Swimming Upstream*.

“If my mother tells us how much she wants a grandchild one more time, it may be the last time we talk to her. I know she doesn’t consciously mean it, but I’m sick of the guilt.” - Andrew, 35

Some couples feel the pressure from the parents as they ask – continually – when they will deliver them grandchildren. Other couples feel the pain of the things their parents say which hurt or frustrate them.

So why the stress? It’s a question that has really never been asked before – so I asked it when researching my book *Swimming Upstream: the struggle to conceive*. I’ve since found out that no-one has really written before about the issues that come up, including:

- **When are you going to have grandchildren?** As much as society expects our generation to be parents, there is also an expectation on our parents’ generation to be grandparents. Unfortunately, that can translate into pressure on you if your parents hear the dreaded question ‘when are you two going to have grandchildren?’ And it can be frustrating if your parents are overt about looking at your potential children as THEIR grandchildren. That can leave you feeling like you’re not an important part of the process, but rather, the ‘couriers’.
- **The usual misunderstandings.** The parent-child dynamic can be a challenging one at times anyway, let alone when you throw in a curveball like infertility, for which there are few road maps to understand what’s up ahead. Your parents are people too. They can sometimes carry similar misunderstandings about what you’re going through as everyone else. Unless they have a reproductive history that says they have been there before, they may not be able to relate to you. They may believe the four fertility myths our society has (more about that in *Swimming Upstream*).
- **They may not know what to do or say.** It can be a tough job to sit back and watch someone you care about suffer. It can be like that for your parents. They may be watching you go through hell and not be sure what to do. Some parents face a dilemma. They want to give you space because you’re your own person, so they don’t say something. But they may start feeling by not saying anything they’re not actually helping. Or they may be trying to help, but just don’t know how to relate. They may press too hard, only to be met with a reaction that they don’t know what to deal with. Or they may be trying to say the right thing, but their misunderstanding of your situation means that they say or do the wrong thing.
- **Talking to your parents about a topic you don’t talk about anyway.** Few people are comfortable talking with their parents about intimate issues anyway. Perhaps it’s the generation gap. Most generations in history haven’t really liked talking to their parents about much, let alone intimate issues. Perhaps it’s a carry-over from our teenage years when the last thing in the world we wanted was to think of the possibility that our parents ‘did it’. Some people find it hard enough to hold a polite conversation with their parents for more than 15 minutes about safe topics, let alone sitting them down and discussing a topic like this. While you’re suffering and wondering if you’ll ever have children and be a parent, your parents may be starting to wonder as well. And it may be harder for them than you think. One thing that can be important in dealing with your parents is to understand what they are going through, as they are watching you struggle to have a family.

- **The inability to help you out.** Your parents may feel helpless because they can't fix your problem. As your parent, it's their role to fix problems of their child, or make them feel better, kiss it better, put a Band-Aid on it or at least to notice when things go wrong. They may be used to helping you out – and may have done so since you were a child – but there's little they can do to fix your situation.
- **Guilt.** If infertility is a hereditary issue, it's going to hit either your or her parents hard. They may feel responsible for your suffering. Your genes (and any problems with them) are genes you got from them, so they may feel that they are the source of your problem. People can become very confused about what it means to have a genetic condition. It can be genetic in the sense that it is coded into that person's genes – uniquely constructed in their genes, not necessarily because they inherited it from their parents and therefore it is the parents' fault. Some parents may also wonder if they've done something wrong while you were growing up by letting you take on activities which may have somehow caused your fertility problems. Or they may not say anything, but they feel it and they act like they feel it. And sensing that your parents may be feeling this without talking it through can produce real tension.
- **Continuing the family name.** Some parents feel the pain of the disconnection of the family name. Your trouble may just be the start of their intense disappointment in the end of the family line. Their response may be very different to the disappointment that friends share with you. If friends realise you won't have kids, they're disappointed for you. When your parents realise there may not be any kids and it could mean the end of the 'family line', the disappointment affects them too. So they may be living with two kinds of pain – one that they can't help you and another that their family – in name – may end.

There are also other issues that arise within the wider family, depending on whether or not there are other grandchildren already around the place.

Parents who have no grandchildren yet

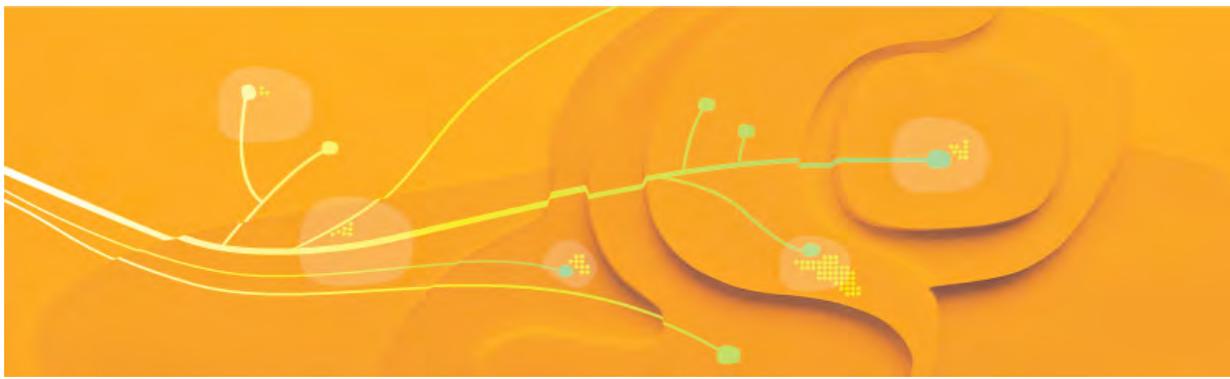
While your immediate circle of influence may feel like it is churning out kids that are a constant reminder to you of your own lack of children, your parents are probably moving in circles that are constantly pumping out grandchildren – that are a constant reminder of their lack of grandchildren. They have no brag book to show the other grandparents at morning tea.

And that can hurt if you may miss out on what everybody else is doing. They may be feeling similar things to you in being isolated from **their** friends.

Parents who have other grandchildren

"I would get very angry because we couldn't celebrate the birth of a grandchild because we were trying to be sensitive to our son who couldn't have kids. I felt sorry for our other son because we didn't seem to go overboard and share his joy as much as we wanted to. It was like walking on eggshells. I hated it." – Carol, 56

If you're struggling to conceive and your brothers or sisters aren't, your parents may have to deal with splitting their emotions. They may feel that they have to be excited enough to please the



grandchildren they have, but still sensitive enough to not be too over the top and isolate you. Some do it well, others don't.

Some ideas to help you deal with this issue

The ramifications of how you handle any conflicts or hurts within this relationship are far more serious than friends. Friends you can walk away from (if you have to). Family is different. When you're dealing with your parents or family, you may still be dealing with the same misconceptions as everyone else, but there's more emotional investment in it because it's so close to home.

While we have a whole section in *Swimming Upstream* dedicated to providing advice to help you deal with this most sensitive relationship, here are a few starting points:

- Try to get them to understand what you're going through (and I realise that may be tough!) You may find opportunities to share information about the effects of fertility problems, and sometimes even just a few facts can help relieve confusion. Reading a book like *Swimming Upstream* will help them understand what you're going through. One grandparent-in-waiting who read *Swimming Upstream* said, "I would suggest to every couple in IVF to buy your book for their parents. IVF, like the birth of a baby, is a family situation."
- If your parents make comments that reflect misunderstandings and hurt when you hear them you can consider letting them know how their comments affect you. They may not understand that they are hurting you at all.
- Your parents may be really wanting to help you but don't know how. They may be pleased to be given the opportunity to support you by helping out in practical ways.

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



5. iVFlings

We are excited to announce the launch of the iVFling forum. This is a forum we have created so other iVFlings – can have regular contact with each other. If you are an IVF child or adult and would like to make contact with other iVFlings, please visit the iVFlings page on the new Access web site:

<http://www.access.org.au/?p=189>

Our group are strong advocates for the inclusion of IVF in the public policy agenda especially through the school education system. We would love to make this group even stronger by hearing from you on what issues around fertility you are passionate about or just to have a chat.

We welcome you to the forum and look forward to sharing ideas with you soon!

Candice Reed and Rebecca Featherstone Jelen (iVFlings)

6. UWS needs your help!

We sometimes promote research studies that you may wish to be involved in, as they can help improve treatment for infertile couples across Australia.

University of Western Sydney in collaboration with some IVF units are undertaking a study examining if acupuncture can improve live birth rates for women undergoing IVF.

They are seeking volunteers undergoing IVF and not planning to use acupuncture, and willing to share information on their outcomes and wellbeing. You need to be less than 43, undergoing a fresh cycle, have had two or more unsuccessful embryo transfers and frozen embryos.

Please contact Sarah for information s.fogarty@uws.edu.au or 0414 357 363.



7. IVF take-up rate surges

The take-up rate of assisted reproductive technologies, such as IVF treatment, has risen dramatically over the past five years, new research has revealed.

Read the full story at: <http://www.abc.net.au/news/2011-11-09/ivf-figures-up/3653756>



8. Access in social media - Facebook

We have now hit the 100 Likes mark in Facebook. It's great to connect with members in this way.

If you haven't already connected with us, please visit us at <http://www.facebook.com/pages/Access-Australia/139771856113076>. If you have already linked up, please let us know what sort of discussions or information you'd like to have on Facebook. 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!

News articles:

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

- Researchers examine 'fertility switch', NursingTimes.net, UK
< <http://www.nursingtimes.net/nursing-practice/clinical-specialisms/womens-health/researchers-examine-fertility-switch/5037603.article> >
- IVF treatment helping dreams come true, Herald Sun, Australia
< <http://www.heraldsun.com.au/news/more-news/ivf-spreading-even-more-joy/story-fn7x8me2-1226190567974> >
- Your sperm are what you eat, Reuters, USA
< <http://www.reuters.com/article/2011/11/18/us-sperm-idUSTRE7AH2H820111118> >
- Couple tell of devastation at IVF blunder, Wales Online, UK
< <http://www.walesonline.co.uk/news/wales-news/2011/11/23/couple-tell-of-devastation-at-ivf-blunder-91466-29824234/> >
- Guys, watching your diet may boost IVF success, study suggests, msnbc, USA
< http://www.msnbc.msn.com/id/45381619/ns/health-mens_health/#.Ts7ICk_wGWU >
- Racing biological clock has its risks, Sydney Morning Herald, Australia
< <http://www.smh.com.au/national/health/racing-biological-clock-has-risks-20111119-1nof3.html> >
- Counselling a must for couples undergoing IVF, Hindustan Times, India
< <http://www.hindustantimes.com/Lifestyle/Wellness/Counselling-a-must-for-couples-opting-for-IVF/Article1-771492.aspx> >
- To freeze or not to freeze, Daily Telegraph, Australia
< <http://www.dailytelegraph.com.au/news/ivf-debate-to-freeze-or-not-to-freeze/story-e6freuy9-1226200030851> >
- Rising age of mothers and IVF leading to earlier births, Irish Times, Ireland
< <http://www.irishtimes.com/newspaper/ireland/2011/1118/1224307765883.html> >

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