

(14:54:07) **ModeratorAnita:** Welcome to our ask the session, the session will begin in around 6 minutes

(14:57:30) **DanT:** hello

(14:58:03) **Caz:** Hi Dan!

(14:58:05) **Nat:** Hi Dan.

(14:58:13) **ModeratorKendall:** Hello Danielle, hi all

(15:00:21) **ModeratorAnita:** Please welcome our expert Aaron Thompson to the session

(15:00:32) **ExpertAaron:** thanks

(15:00:39) **ExpertAaron:** be gentle

(15:01:52) **Nat:** Welcome Aaron!

(15:04:01) **Caz:** To kick things off here's a question we received earlier for Aaron

(15:04:01) **DanT:** okay i have question...

(15:04:16) **Caz:** A question we received earlier from Lyndon: What is the life expectancy of stored sperm and what is the approximate 'depreciation rate' - when does it become less effective? A data source would be great.

(15:04:45) **Caz:** Aaron's Answer - Essentially for longer than a life time so the specialists say. There have been case reports of people using their sperm well over 20 years after freezing and having viable pregnancies. There is a rapid depreciation in the first 48 hours of approximately 50% then the attrition is quite slight. Remember though you only need one for a pregnancy if you have a low sperm density 10×10^6 / ml then that is still millions. I think the best data source would be to speak to the fertility clinic who stored your semen they should have a report on your semen analysis.

(15:05:38) **140196:** Hi Aaron I'm coming up 30 and I have met someone after having treatment for AML and he would like a child. I'm infertile and would like to know if there is any way we could achieve having a baby?

(15:05:39) **Automated Message:** *1RebeKah2 logs into the Chat.*

(15:06:27) **ExpertAaron:** If you are infertile there may still be options as a female to carry a child in this situation, would you consider someone else's eggs - menopausal women whilst they cannot conceive naturally can generally carry a donor pregnancy through IVF. So if you are able to you might like to use your mother's / sister's / cousin's eggs so the child might be genetically similar to you.

(15:06:45) **Automated Message:** *Dukes logs into the Chat.*

(15:07:04) **140196:** Is there any risk to me?

(15:08:02) **ExpertAaron:** If you did have tbi with your AML they are some increased risk for pregnancy in terms of low birth weight & miscarriage for the baby.

(15:08:22) **ExpertAaron:** There can be if you have had a lot of red drugs & radiation to the chest

(15:08:39) **140196:** can the aml come back?

(15:08:51) **ExpertAaron:** you may need to have cardiac monitoring during the delivery

(15:09:03) **140196:** I did have tbi and it effected my lungs is this a concern?

(15:09:24) **1RebeKah2:** Is this the same if you had radiotherapy and chemo for hodgkin's?

(15:09:47) **ExpertAaron:** Not from pregnancy

(15:09:55) **Automated Message:** *anto logs into the Chat.*

(15:09:59) **1RebeKah2:** Does this apply to women that have had chemo and radiotherapy for hodgkin's?

(15:10:00) **Automated Message:** *614554 logs into the Chat.*

(15:10:06) **ExpertAaron:** yes anyone who has these drugs or radiation

(15:10:47) **ExpertAaron:** to the chest

(15:10:48) **140196:** Is there a percentage that you know of of how successful it would be?

(15:10:58) **Automated Message:** *627037 logs into the Chat.*

(15:10:59) **Automated Message:** *bill logs into the Chat.*

(15:11:39) **ExpertAaron:** not in your particular circumstances there hasn't been direct study to give data in Australia

(15:12:09) **ExpertAaron:** general ivf rates are between 25 to 40% success

(15:12:28) **Caz:** A question we received earlier from Lyndon - At what time should I seek to have my sterility re-tested? Post treatment, maintenance phase, how long after oral medication ceases? When is the right time? I just finished my last does of chemo on the Fralle protocol and now have 12 mths of oral methotrexate and mercaptopurine remaining.

(15:12:51) **Caz:** Answer to Lyndon's question - Unfortunately that means you still have 12 months of chemotherapy! You can essentially test your semen anytime but ideally for optimum results you would test 6 months to 2 years off treatment and if you are still a teenager I would test in later adolescence / early adulthood again just to be sure. You could also have your doctor test your sex hormones to see if you are having poor sex hormone function.

(15:13:37) **DanT:** Aaron if you have already had 6 months of chemo and are still fertile, but haven't had eggs harvested. Is it still okay to harvest eggs just in case you relapse?

(15:14:44) **ExpertAaron:** You need at least 3 menstrual cycles to safely do IVF but it would also depend on the chmo so it may be worth discussing this with a fertility specialist

(15:14:54) **Dukes:** Hi Aaron - do you know if there is any research into whether having had chemo in the past would increase the risk of 'damaging' the development of a baby (eg would the chemo have harmed the DNA in

the eggs etc). I have had high dose chemo and auto stem cell transplant for Hodgkin's nearly 5 years ago (and prior chemo and radio about 5 years before that). Having recently being married, having children is now something I've started to think about...

(15:16:21) **ExpertAaron:** there is no increased for people in conceive naturally if they have had chemo there is an increased risk for women who have had radiation to fields including the uterus because of low birth weight

(15:16:58) **Automated Message:** *Jessica84 logs into the Chat.*

(15:17:13) **ExpertAaron:** Interms of ICSI procedures there is no available studies so If you have to do sperm injection into the egg it is unknown if there is a risk.

(15:17:48) **ExpertAaron:** that was for dukes question

(15:17:53) **Dukes:** What's ICSI procedures mean?

(15:18:23) **ExpertAaron:** intracytoplasmic sperm injection where they inject dna material into the egg to fertilize

(15:18:29) **ExpertAaron:** duke again

(15:19:08) **Caz:** Another question we received earlier from Lyndon- What is the expected financial cost of my partner requiring IVF if I'm sterile due to my cancer treatment? I understand this may vary due to individual health cover.

(15:19:27) **Caz:** Aaron's Answer to Lyndon's question - Real answer is ask your local fertility clinic as every place is different but you could expect to pay in the vicinity \$1500 - \$3000 per cycle

(15:20:14) **DanT:** Dukes - i know quite a few people who have had a natural birth a few years after treatment and there babies are gloriously healthy!

(15:20:17) **bill:** Doesn't medicare cover any of the cost?

(15:20:36) **ExpertAaron:** Yes they do those amounts include that

(15:21:00) **ExpertAaron:** you may also get it cheaper if you have private cover for day hospital etc

(15:21:13) **ExpertAaron:** sorry that was for bills question

(15:21:58) **Dukes:** DanT - that's great to hear! I am quite nervous about the idea of it (assuming I could even get pregnant given all the treatment I've had), as I'm concerned that my DNA is damaged or something due to my past cancer treatment, so I'd hate to think that a baby we conceived would be born with major health problems as a result. It would make me consider not trying....

(15:22:59) **ExpertAaron:** It is important to remember that you need to confirm that you are infertile just because you are told you probably are that does not mean you are. You should always practice safe sex as well.

(15:23:03) **bill:** There seems to be so many IVF specialist's centres around these days. How do you know if they are reputable and suitable for you? How do you decide on one?

(15:23:08) **DanT:** Dukes - have you confirmed whether you are fertile or not?

(15:23:29) **ExpertAaron:** Bill If you conceive naturally you have the same risks as the rest of the population

(15:24:24) **ExpertAaron:** The fertility society of australia has a specialist interest group that could point you in the right direction. You can find this group via google

(15:24:42) **ExpertAaron:** That was for Bills question

(15:24:58) **1RebeKah2:** Hi, I was wondering if there are any health risks associated with using hormones during procedures such as IVF? Is there a risk of cancers such as breast cancer?

(15:25:05) **bill:** That's helpful, thanks Aaron

(15:25:24) **Dukes:** I'm not sure yet. I have been to a IVF specialist a few months ago and have been having blood test to check hormone levels - I will be going to see the specialist with the results next Tuesday. I'm a bit unsure as to how I would know exactly if I was 'infertile'. I was told at the time of treatment there was around a 90% change that the high dose chemo would make me infertile, but I still am hoping.

(15:26:05) **ExpertAaron:** Rebekah Yes there can be a risk if you do this while you have certain cancers but your oncologist should be in the loop any of these sorts of discussions

(15:26:25) **Automated Message:** *fpinzone logs into the Chat.*

(15:26:38) **anto:** If people are particularly worried about how the DNA in their sex cells have been affected after high dose treatment, is there any tests they can take to test their DNA, or should they have any extra tests during pregnancy to allay their fears?

(15:26:42) **ExpertAaron:** Sorry Rebekah I miss read no there is no increase risk of getting these cancers that I am aware of

(15:27:13) **Automated Message:** *alice logs into the Chat.*

(15:27:27) **DanT:** Hi Rebekah - I don't know your individual circumstances but I'm on HRT and my endocrinologist and gynaecologist both have shown me studies that HRT only increases the risk of breast cancer in women who are naturally menopausal - ie they shouldn't have those hormones in their bodies. Younger women SHOULD have those hormones. Don't know how it affects IVF though...

(15:29:04) **ExpertAaron:** To cover a few answers there are couple of ways we can use to tell if you are infertile check testicle size & quality, check sex hormones via blood test and a semen analysis (whilst this is not perfect it can tell us a fair bit

(15:29:13) **1RebeKah2:** I have had full mantle radiotherapy and chemo for Hodgkin's. I have been told that there is an increased risk of breast cancer with this. Could using hormones further increase that risk?

(15:30:45) **ExpertAaron:** To answer antos question there are a number of tests they undertake during ivf if you are doing it that way they can help allay those fears, otherwise there are a number of tests that are part of normal pregnancy assessment that would do the same

(15:31:03) **Dukes:** DanT, do you mind asking why you are on HRT? Is that because you found out that due to treatment, your hormone levels were low? I'm just wondering if this is something I should be thinking about discussing with my doctor, as I'm fairly sure that mine are.

(15:32:08) **ExpertAaron:** Rebekah yes there is a slight increase risk you should speak to your specialist to set a plan for routine screening if you are concerned

(15:32:36) **140196:** Does it make a difference with IVF if you received your stem cells from a male donor?

(15:34:01) **DanT:** Dukes - I had very high dose chemo and stem cell transplant (nearly 6 years ago) and have been confirmed infertile as a result. I am in my twenties so it is very important that I have oestrogen, in combination with progesterone to protect me against heart disease and most especially osteoporosis

(15:34:04) **ExpertAaron:** 140196 no it is more the chemotherapy & radiation although if you have had GVH it may also place you at increase if it has upset your natural internal environment in your uterus

(15:35:34) **ExpertAaron:** Dan T In this situation you may consider using a relative's eggs to try to conceive a child for example freezing your mother's or sister's eggs so you can have a genetically similar child

(15:35:34) **DanT:** Without HRT my bones would deteriorate, so any risks associated (and none have been identified for this age group) are insignificant compared to the risk of heart disease, osteoporosis.

(15:35:59) **Dukes:** Aaron, given what you said to Rebekah about an increased risk of breast cancer with IVF coupled with an increased risk of breast cancer due to combined radio and chemo for Hodgkins, it makes it sound like IVF is something to think long and hard about before undertaking due to these combined breast cancer risks. Do you know if there are any other options of doing IVF with a lower level or stimulating hormones or similar (in other words, is there any way to try and reduce that increased breast cancer risk associated with IVF?)

(15:37:20) **DanT:** Hormones also produce collagen for the skin and increase libido. But it is very important to talk to an endocrinologist or fertility specialist to check your sex hormones and they will prescribe what is most appropriate for you

(15:37:21) **ExpertAaron:** Dukes - Not at all these are only slightly increased risks so it is still a very viable option.

(15:39:00) **1Rebekah2:** Have there been any developments in conceiving using re-grafted ovarian tissue? I had some ovarian tissue frozen prior to chemo.

(15:39:12) **ExpertAaron:** Duke - there are a few different ways of undertaking infertility treatment so if anyone is concerned they can speak to a fertility expert also to discuss this

(15:39:46) **DanT:** I think there has been a few births in the UK - not sure though Rebekah

(15:39:59) **ExpertAaron:** Yes there are a number of significant advances in this area with a few live births, there is much work being done on this

(15:40:00) **Dukes:** DanT, that is a real eye opener for me. My doctor has never mentioned seeing an endocrinologist or similar all of these years, even though I suspect it is an issue for me, especially when you describe some of the symptoms of low hormones. Did your haematologist put you on to an endocrinologist or is this something you found out yourself, as I am also in my 20s and think that this is something that I should investigate further.

(15:41:13) **ExpertAaron:** Dukes - You can get a simple blood test to check this, you can even get your GP to assess this as a cursory review

(15:42:04) **DanT:** Dukes - definitely investigate further. My doctor referred me to both an endocrinologist and gynaecologist and both told me I need to be on HRT which is just a case of taking a pill everyday. If you have never seen one I really think you should raise this with your doctor or GP and get a referral. They will test your fertility and hormone levels, including thyroid function.

(15:42:08) **Dukes:** Good advice Aaron, thanks.

(15:43:26) **ExpertAaron:** It is important that young women who have treatment who are menstrual after their treatment consider that they may be more likely to go into menopause early than the rest of the population. It is worth meeting with a fertility specialist after your treatment anyway if you feel that having a family is important to you

(15:44:21) **ExpertAaron:** You may be able to start family planning early or store eggs or embryo just in case

(15:44:31) **DanT:** Is there a list of fertility specialists available Aaron?

(15:45:29) **ExpertAaron:** Dan T yes I recommend you go to groups <http://www.access.org.au/> or Australian fertility society of Australia

(15:45:42) **Dukes:** Aaron if that is the case (going into premature menopause) - then do you usually suggest HRT? I guess I'm concerned that with the increased risk of breast cancer associated with the cancer treatment that I have had, that going on HRT increases that risk significantly.

(15:46:11) **ExpertAaron:** these are also really good general websites for information about fertility - <http://www.fertilehope.org/> <http://www.myoncofertility.org/>

(15:47:27) **DanT:** Ther ehave been no studies that show an increased risk of breast cancer in younger women. The risk occurs when older women (ie those who are naturallymenopausal) have hormones running throughout their bodies when they shouldn't.

(15:47:44) **ExpertAaron:** Dukes you really need to discuss that with your specalist & an endocrinologist / fertility expert there are number of complex issues here that I would need more information to provide you an answer with

(15:48:05) **DanT:** Younger women require hormones for normal bodily function - ie bone and heart prttection

(15:48:50) **DanT:** and to have great sex 🤔

(15:48:54) **DanT:** hehe

(15:49:19) **ExpertAaron:** Dukes but to put into perspective if you have ovarian insufficiency and need hormone treatment if you are still actively sexual you need a higher dose to protect against pregnancy

(15:49:49) **1RebeKah2:** Dan T, have you had any side effects with HRT?

(15:49:51) **ExpertAaron:** sorry protect against pregnancy doesn't sound very nice

(15:50:31) **DanT:** not that I'm aware of.

(15:50:36) **DanT:** so no

(15:50:54) **DanT:** my bone density has increased since i began on them so that's a good thing

(15:51:03) **Dukes:** Yes all good points!!! Also guys for any of you who are in Adelaide, there is a clinic run out of the QEH for Hodgkin 5 + year survivors, who I'm fairly sure will help to get through the maze of this a bit. I'm going to see them later this year so hopefully this will help me work out some things.

(15:51:08) **ExpertAaron:** Rebekah - very similar to the symptoms you can have with the pill

(15:51:37) **Dukes:** Sorry forgot to say, its called the "Late Effects Clinic". You just need a referral from your GP.

(15:51:44) **DanT:** I had much more side effects when i was on the pill!!!

(15:52:10) **ExpertAaron:** Dukes - a agree nearly every state has a long term follow up clinic where you can ask these questions for those in queensland that is me

(15:52:10) **DanT:** weight gain, moodiness etc

(15:52:18) **ModeratorAnita:** 8 minutes until the end of our session so any last questions please

(15:52:45) **1RebeKah2:** Dan T did you experience any menopausal symptoms?

(15:53:16) **DanT:** maybe hot flushes but not sure cos it was hard to know what was treatment related and what was hormonal

(15:53:19) **1RebeKah2:** prior to starting HRT?

(15:53:24) **DanT:** insomnia

(15:53:47) **1RebeKah2:** Any night sweats?

(15:53:53) **DanT:** I honeslty don't notice HRT ...

(15:54:04) **DanT:** not really

(15:54:17) **Automated Message:** 140196 logs out of the Chat.

(15:54:17) **DanT:** but i could have and just put it down to treatment

(15:54:24) **Automated Message:** 699419 logs into the Chat.

(15:54:46) **Caz:** A question we received earlier from Lyndon - At what time should I seek to have my sterility re-tested? Post treatment, maintenance phase, how long after oral medication ceases? When is the right time? I just finished my last does of chemo on the Fralle protocol and now have 12 mths of oral methotrexate and mercaptopurine remaining.

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(15:55:01) **Automated Message:** Ashley logs into the Chat.

(15:55:35) **ExpertAaron:** Because we are nearly finished I am going to say this again you need to confirm if you are infertile, you need to practice safe sex and you need to consider speaking to a fertility expert if you would like to have children in your future to know if there is anything you should be aware of such as premature menopause

(15:56:09) **Ashley:** Hi Expert Aaron

(15:56:47) **Ashley:** I know you have a squillion question you are answering but I have one..

15:57:05) **Ashley:** My partner had a bone marrow transplant 12 months ago

(15:57:22) **ExpertAaron:** Go ahead if you have questions i haven't answer you can send your questions via LF

(15:57:33) **DanT:** yeah i agree Aaron, it's really i portnat to talk to a fertility person about all this, cos everyone is different and they can give you specific advice dpending on your treatment, age and plans for the future.

(15:58:00) **Ashley:** We had his fertilyaty tested 2 weeks ago and he is indeed sterile... We were told that you can only keep a sample for 7 years

(15:58:20) **Ashley:** Is this the case?

ExpertAaron: that may be a local rule but essentially you should be able to store the semen much long er there have been case report s of pregnancies after 20 years

(15:59:42) **DanT:** is it a financial / space requirement Ashley?

(15:59:50) **Ashley:** So it could vary from state to state as well as different companies?

(16:00:09) **ExpertAaron:** Also it is important to ask for a report on the quality of your frozen sperm as if he is infertile you may consider storing his dad or his brother's sperm as well.

Dukes: Thanks everyone for sharing their stories and advice, it's certainly helped me.

(16:00:37) **Ashley:** It is less about money - we will do everything in our power to make sure it's there but more about timelines

(16:00:44) **ExpertAaron:** Ashley it is not a rule I have ever heard of I would be very surprised as generally if you pay they store

(16:00:45) **DanT:** Dukes - good luck with it all!

(16:00:46) **ModeratorAnita:** Thank you so much for your time today Aaron, what a great session this has been. If you feel your questions were not answered please email us at revive and we will forward to Aaron our expert.

(16:01:10) **ExpertAaron:** Thanks everyone for your time

(16:01:14) **DanT:** Thanks Aaron!!!!

(16:01:17) **Ashley:** Thanks expert Aaron

(16:01:19) **ExpertAaron:** best of luck

(16:01:20) **Dukes:** Thanks DanT - PS it's Janica - I ended up getting the job with LFA!

1RebeKah2: Thanks Aaron

(16:01:28) **Nat:** Thanks Aaron the Expert!

(16:01:29) **ExpertAaron:** sorry if I confused anyone

(16:01:33) **699419:** Thanks aaron

(16:01:36) **DanT:** hahahah well done!!!

(16:01:40) **ModeratorAnita:** A copy of today's questions and answers will be posted on revive next week