Fertility Related Psychological Symptoms

Some patients with cancer will need cancer treatment that may affect their ability to have children. This fact sheet aims to provide information about the psychological symptoms associated with fertility problems or undergoing fertility treatment during and after cancer treatment. It will discuss how you might feel if you are told your treatment may result in difficulties having children of your own in the future. It also outlines the effects of fertility preservation and will provide you with tips on how you can cope with this information.

The information does not replace talking to your doctors or nurses. It aims to act as a tool to help you prepare questions you can ask your healthcare team.

Loss and change

Trying to come to terms with fertility issues during or after cancer can be difficult. Being told you could have problems conceiving a child and/or carrying a baby will affect everyone differently. Some may cope well with this news as they are more focused on having treatment and being cured while others have no interest in having a child (or more children). However, others suffer a huge sense of loss and change to their life. Plans for the future, especially with respect to having a family, may become much more complicated.

It is very painful to lose the ability to make choices you thought were a certainty. It can be even more upsetting if you have to make choices about fertility at an age when parenthood is not on your radar. You may go through a roller coaster of upsetting emotions (e.g. sadness, anger, frustration), which can have a significant effect on your day-to-day life. Knowing you may not be able to have children can also affect how you feel sexually. It can change how you feel about yourself, a partner and your body (your sexuality).

Your feelings and reactions

Fertility is so highly valued in most cultures and the desire to have a child is one of the most basic of all human needs. Taking away this possibility can leave both men and women feeling lost, vulnerable, angry, isolated and depressed. Trying to look happy when all you feel is sadness, loss and desperate may be impossible for someone facing infertility. It would be very normal to ask the question, ‘how can this possibly happen to me after already having to deal with a cancer’ diagnosis?’
All these possible feelings can happen at different stages of a person’s cancer journey and treatment. For example, at diagnosis, the end of treatment or later on when they want to have a baby.

The roller coaster of emotions many people go through when faced with infertility have been well researched and documented. Health professionals often refer to these difficult emotions as “fertility related psychological distress”.

Fertility related psychological distress might be heightened by several factors including:

- Low self-esteem caused by repeatedly trying to have a baby but failing to achieve this.
- Financial worries - cost of fertility procedures can become a huge issue for many couples and only add to the existing stress.
- A real or feared loss of intimate relationships with your partner, family members and friends.
- The fertility preservation process itself (intimate and difficult procedures such as hormone injections and egg collection).
- Learning close friends have fallen pregnant easily or seeing couples with babies/small children (this can be incredibly painful for couples having difficulty conceiving). Not feeling comfortable talking about your infertility problems.
- Other psychological stress involved with having a potentially life threatening illness.

How you react to having fertility problems will depend on:

- Whether or not you already have children
- Your age
- Whether or not you wanted to have children or add to your existing family
- Whether or not you have a partner
- The support you receive

Some people will be very young when they are told they may have fertility issues. They may not be ready to think about this issue or even know if they want children in the future. As hard as it may be it is still important to know what your options are for preserving your fertility. Most doctors will advise you do what you can to preserve your fertility. You may not think you will want children at the time of your treatment. However, feelings can change, as you get
older. Down the track you may decide you want children, so keep your options open.

**Talking about infertility**

Whilst some people are comfortable talking about their infertility, others want to remain private about being unable to conceive. Discussing infertility is still a taboo topic in some societies. Some couples feel they must hide the truth about their infertility from close family and friends. Many say that not being able to have a child makes them feel like a failure so it is easier to keep it secret. However, infertility is not something people can usually control. They should not be made to feel embarrassed or uneasy about it.

Your reactions and feelings will depend very much on your individual situation. But the important thing is you are well informed. Knowing why you may be infertile, what can be done to preserve your fertility and who to talk to about your feelings will help you feel more in control and able to cope. Don’t be afraid to ask your medical team questions. They will want to be sure you are aware of all options and help available to you. Seek professional counseling if necessary. You may also find it helpful to read our fact sheets about preserving fertility in men and women having cancer treatment.

**Others reactions**

Overall most people will want to support you and help you come to terms with the possibility of not being able to have children. However, you may need to prepare yourself for comments or reactions you were not expecting. For example, “At least you are still alive” or “Be grateful for what you have and not for what you can’t have”. Others may try to make you feel better by suggesting having children is only hard work so you are lucky not to have them.

Comments such as these can be confusing and hurtful. They can make you feel very alone and angry. You may feel like nobody understands how painful it is not to have the choice about having children. However, most people do not intend to upset you. They will be aware you are struggling but may not know what to say to help you.

Usually the best way to deal with your feelings in this situation is to be honest with those close to you. Let them know how you feel and express your needs. Most people will be relieved to know exactly how to best support you.
Intimate relationships

Cancer related infertility and changes to your sexuality could put a lot of pressure on your intimate relationships. If you have a permanent partner you may find you both go through a significant change in your relationship. Emotions such as anger, sadness, frustration, fear and loneliness can affect you and your partner.

How you both cope with these feelings and changes will depend a lot on how strong your relationship was before you had cancer. Communication is often the key to keeping the relationship from falling apart. Some couples find talking very difficult and may avoid it at all cost. However, if you can push through your fears and talk to each other about your feelings it is likely to make a big difference to how close you stay. Your opinions about what to do may differ but with time you may be able to find a way to cope with your situation together.

Seeking advice from a fertility counselor or psychologist is often very helpful for couples that want to have children.

Starting new relationships when you have been through cancer and may be infertile can be frightening. You may worry about telling the person about these things. It is only natural to wonder whether or not a potential partner will not be interested in you if they find out you might not be able to have children. Knowing when to bring the subject up will be difficult. Early on in the relationship you won’t want them thinking about being with you long term. But most people worry about leaving the conversation too long and not being up front from the start too.

It can help to chat to those close to you about the right time to talk about your situation. Or seek professional help from a fertility counselor who has experience with others who have had to do this. Try to stay positive as you may still have opportunities to have a child naturally or using assisted reproductive treatment(s). You may find having children is not a priority for your or your partner or that you are willing to look at other ways of having children such as fostering or adoption.
Sexuality and infertility after cancer

Cancer often affects body image, self-esteem, and your interest in sex and/or your ability to have sex. In other words it affects your sexuality. If infertility is also an issue, this can cause further sexuality problems.

Men may have problems with getting an erection or maintaining an erection. Women may suffer painful intercourse or no longer be able to tolerate intercourse. Fatigue, weight loss or gain, scars, hair loss and many other things can contribute to having negative feelings about being intimate and close to someone. Knowing you may not be able to have children can cause feelings of inadequacy, being unattractive and letting your partner down. It can take time to accept any physical and emotional changes that cancer can bring. Being patient and kind with yourself and your partner (if you have one) will help you cope better. Becoming comfortable with your sexuality again takes time.

The following tips may help:

• look after your body which includes eating well, getting plenty of sleep and exercising regularly
• make time to be with yourself and/or your partner: e.g. go on a date or have a massage
• surprise each other with small gifts or a special dinner or movie
• try to make time to relax and keep stress levels low – mediation, deep breathing, yoga and massage all promote relaxation
• explore your sexual desires slowly, think about what used to make you sexually excited and try to allow it to happen again
• take a shower or bath together
• be adventurous: experiment with sex aids, oral sex and masturbation
• don’t be afraid to let your partner know you just want to cuddle or kiss now – intimacy does not have to end in intercourse
• talk, talk and talk more to your partner about how you feel

These suggestions may not work all the time. There will be times you just feel to worn out or upset no matter how hard you try. Try to accept these times and have faith you will not feel like this forever. If nothing seems to help then seeking professional help from a trained sexuality counselor or psychologist can also be helpful. Or find support from professionally run support groups. Knowing you are not alone and can discuss your problems with others in a
similar situation is often a great comfort. Refer to the paragraph at the end of this fact sheet about where to get further help and information.

Talking to others

Many people with cancer say that it helps a lot to speak with others in a similar situation to you. There are several avenues of support available to people with cancer. For example, face-to-face or online support groups and one to one telephone support. At first it may feel uncomfortable sharing your fears about your cancer and fertility issues. However, if you find the right support you may find you feel better able to cope after talking with others. Look in the *Where to get further help and information* section to find out more. Also keep the lines of communication open between you and your close friends, family and medical team. Everyone will want to help you as best they can but may need you to let them know what you need.

Questions for your doctor

Raising the topic about fertility preservation can be difficult but it is important you do. These questions may help you begin the conversation:

- How will my cancer treatment affect my chances of having a child in the future?
- Are there ways of preserving my fertility?
- Will my treatment affect my sexuality?
- Who can I talk to about my treatment and the possible fertility side effects of treatment?
- Can you recommend a fertility specialist?
- Where can I find support for coping with fertility issues?
- Who can I talk to about my sexuality, infertility and how I am feeling?

Where to get further help and information

This fact sheet has provided you with an overview of how you may feel if your cancer treatment affects your fertility. It is important you find out as much as you can to help you cope the best you can.
For more detailed information please refer to our other factsheets and the following excellent resources:

• Fertility Society of Australia (http://www.fertilitysociety.com.au/)
• Relationships Australia (www.relationships.org.au/)
• CanTeen Online Support Services (www.canteen.org.au)

You may also like to call a Cancer Helpline service:

• Australia 13 11 20
• New Zealand call 0800 226 237

Both helplines will allow you to speak with an experienced cancer nurse.