

Battle Weapons for Adolescents and Young Adults with Cancer



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Cover by Nell Hanbury

This book is not intended as a substitute for the medical advice of physicians. The reader should regularly consult a physician in matters relating to their health and particularly with respect to any symptoms that may require diagnosis or medical attention.

About the Author

Hi, my name is Nell and I am a cancer survivor. I was enjoying an independent life, working full time in Sydney as a registered nurse, when I was diagnosed with non-Hodgkin lymphoma in 2013. I was 25 years old. My adult life had barely begun.

I was scared that I would die. At this point in time, I felt that I hadn't really achieved much. I wanted to do so much more. I was worried about the people I would leave behind, particularly my parents. The death of our dear family friend, who was a similar age to me, was fresh in our minds.

Continuing to live in a share house was no longer an option, so I had to move out. My generous grandmother offered her beach house to us; this is where Mum and I lived for the duration of my treatment. My folks live in a country town about five hours from Sydney. Mum literally dropped everything and put her life on hold to save mine.

For health reasons and practical reasons, I chose to stop working. From the beach house, work (where I was now a patient) was a 1.5 hour commute on a good day. Luckily, I was covered by leave entitlements for most of the time I had off.

Every three weeks, I went to hospital as an outpatient to get the CHOP (cyclophosphamide, doxorubicin, vincristine, prednisone). This was the chemotherapy regimen that I was treated with (If you want to have a read about your own treatment, www.eviq.org.au has some good information). The first three medications in CHOP were given through a drip and the last one, a steroid, was given as a tablet which I took for five days each cycle. A few hours after chemo I would be vomiting vigorously, which on one occasion necessitated a mercy dash to the emergency department. My hair starting falling out a couple of weeks after the first cycle. While I didn't feel the loss keenly, it did make me feel somewhat vulnerable and took my self-esteem down a notch or two. Fatigue was a major issue as well. I probably slept for about 12 hours a day, including 'power naps'.

One day during my cancer treatment, while I was lying in bed feeling sick and sorry for myself, it suddenly came to me that my purpose in life, my calling, was to be a cancer nurse. In 2015, I completed a post graduate certificate in cancer and haematology nursing. I now work part time as an oncology nurse and volunteer with

the Leukaemia Foundation as a 'Blood Buddy' – see the Peer Support chapter for more information about this fabulous service.

After finishing treatment I lived at home with my parents for a few years in the Central West of New South Wales where I grew up, to begin rebuilding my life. The loss of independence was definitely one of the most challenging impacts cancer has had and getting it back took longer than I expected. I finally moved out of home (again) in July 2017 after getting my dream job at a cancer centre in Sydney.

An assessment I did for my post-graduate course was an essay about caring for a vulnerable population in the context of cancer; I chose to focus on adolescents and young adults. This assessment, along with my own experience with cancer, inspired me to create a guide filled with the information I have discovered and used along my cancer journey.

While you're reading this guide, please bear in mind the suggestions I have made are only suggestions and based on my personal experience. I, and some other young people I know have found them helpful, but you may not. I hope that you do find something here beneficial, and that reading my story has made you feel like you are not alone in this battle.

As of 2018, I have been in remission for four years.

You can read more about my story here: <http://www.cancer.org.au/about-cancer/share-your-cancer-story/nell-hanbury.html>

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Mental Health

Cancer can be a really stressful time. Because of this, mental illness and cancer can often go hand in hand. In addition, as young people, we are more prone to developing mental illnesses, such as depression or anxiety, compared to other age groups. That is not to say that these issues are inevitable. I was able to maintain good mental health during treatment and beyond. It is really important to look after the mind as well as the body. Being aware of your mental state and using coping strategies may prevent distress later down the path. There are lots of things you can do to help prevent poor mental health.

While some strategies may work for some people, others may not find any of these useful.

If you have any strategies that you know help you cope with a stressful situation, write them down and try using them again to see if they work...

Here are some of my suggestions that have helped me and some of my friends going through cancer treatment:

| Strategy | Purpose | Resources & Further Info |
|---------------------------|--|---|
| Meditation | To relax, reduce stress | Mindful Meditation CD. You can order a free copy through the Cancer Council by calling 13 11 20 |
| Mindfulness | To relax, reduce stress | * What is mindfulness and meditation? http://kidshealth.org/en/teens/meditation.html . * 'Smiling Mind' – mindfulness app or website http://smilingmind.com.au/ (free) |
| Exercise | To improve mood but also has many other benefits including reducing risk of recurrence | Life Now program – Cancer Council WA https://www.cancerwa.asn.au/patients/support-and-services/life-now/ (free). Includes yoga and exercise classes as well as meditation and cancer education seminars |
| Keep a journal/diary/blog | To offload and process emotions | There are a few different ways you can do this including writing down what you're feeling, taking photos or videos of your journey. I kept a diary and took lots of photos. It's interesting looking back and seeing how far I've come |
| Art | Same as above and distraction | * Some hospitals have an art program for patients. Check out if there are any classes in your local community * Scar Stories creative program for 18-35 year olds http://www.scarstories.org/for-patients-survivors sewing, painting, photography (free) |

| | | |
|---|--|--|
| Music | Distraction, reduce stress | Listening to music, playing an instrument, or singing. You could make a playlist with songs which have themes of survival and/or resilience http://www.redkite.org.au/support/music-therapists |
| Hanging out with your pets | Distraction, reduce stress | |
| Audiobooks | Distraction | Borrowbox – app which enables library members to borrow eBooks and audiobooks from the comfort of your own home. You just need your membership number (free) |
| Talk to your GP and/or cancer healthcare team | To offload feelings, get support | There may be a psychologist attached to the oncology/haematology unit. Ask your doctor to be referred to them if you feel as though you would like some extra support. Psychologists can support you through your treatment, provide information and useful tips, and be there to talk to when you are feeling down |
| Ask your doctor whether there is a youth cancer centre or service/health team for adolescents and young adults which you can be referred to | To improve your wellbeing | Information about youth cancer services http://www.youthcancer.com.au/ |
| Redkite | To provide support to young people with cancer aged up to 24 | Redkite offer many services including providing information, professional counselling, and group support. Email: support@redkite.org.au , ph: 1800 733 548, www.redkite.org.au (free) |
| CanTeen | To provide support to young people with cancer aged 12-25 | CanTeen provides a variety of tools to assist you such as counsellors, information, and peer support programs. Email: support@canteen.org.au , ph: 1800 835 932, www.canteen.org.au (free) |
| Headspace | To improve the wellbeing of young people aged 12-25 | Provides info about mental health issues and counselling services which are delivered online, over the phone and/or face-to-face. You can access various health care professionals such as counsellors, psychologists, and social workers. Headspace centres are nationwide. http://headspace.org.au/ (free or low cost) |
| beyondblue | To help people protect | Provides info about mental health issues and support services which are delivered online |

| | | |
|--|--|---|
| | and promote good mental health and wellbeing | (forums, online chat with mental health professional, The BRAVE program for anxiety) and/or over the phone Ph: 1300 22 4636 https://www.youthbeyondblue.com/home (free or cost of local phone call) |
|--|--|---|

If you are having thoughts of suicide or self harm:

- Tell your support network about how you are feeling (family or friends)
- Go to your doctor or go to your local hospital
- Call 000 if an emergency

Crisis Helplines (all available 24 hours):

- **Lifeline** 13 11 14
- **Mental Health Access Line** 1800 011 511
- **Kids Helpline** 1800 55 1800
- **Healthdirect Australia** 1800 022 222

Maintaining Hope

It is totally okay to not have a positive attitude 100% of the time. However, it is important to maintain hope, whatever that might mean for you. This can be challenging if you have suffered a lot of setbacks; have a poor prognosis; or are struggling, emotionally or physically, with treatment. Coping with a cancer diagnosis is a delicate balance of being positive or hopeful, and also being realistic.

Reading stories about other people who have had cancer may be helpful...

<http://www.redkite.org.au/real-stories>

<https://www.canteen.org.au/how-we-help/about-us/member-stories/>

<http://www.scarstories.org/our-scar-stories/>

'Getting Cancer Young' Youtube channel

<https://www.youtube.com/channel/UCIdlYhxjsF4EdjXDsbUm-Cg/about>

I am a devotee of an awesome podcast called Jesse vs Cancer which is about a 29-year-old stand-up comedian who is diagnosed with stage IV bowel cancer. Jesse talks about other stuff as well and is pretty funny. Get it on the iTunes Store or here:

<http://jessevscancer.com/>

Follow cancer 'survivors' on social media:

| Name | Facebook | Instagram | Other |
|--|---|---|---|
| Delta Goodrem Hodgkin lymphoma 18 at diagnosis | https://www.facebook.com/DeltaGoodremMusic/ | https://www.instagram.com/deltagoodrem/?hl=en | https://twitter.com/deltagoodrem?lang=en |
| Tessa James Hodgkin lymphoma 23 at diagnosis | | https://www.instagram.com/tessacharis/?hl=en | |

| | | | |
|--|--|---|--|
| Adam Deans Osteosarcoma 17 at diagnosis | | https://www.instagram.com/adam_deans/ | https://twitter.com/adam_deans?lang=en |
| Ben Bravery Bowel cancer 28 at diagnosis | | https://www.instagram.com/benbravery/?hl=en | http://benbrave.blogspot.com.au/ https://twitter.com/benbravery?lang=en |

It may also be helpful to have a think about some kind of fun activity that you'd really like to do, or an experience you'd like to have, to lift your spirits and maybe cross something off that bucket list. You might like to meet your idol, travel somewhere or have a makeover and photoshoot. My friend decided to go on a cruise (I think the cruise line was called something like 'The Majestic Gastroenteritis'. Haha). Okay, that last part isn't true but cruises really don't appeal to me at all. I would maybe consider getting on board if I was wearing a hazmat suit. But hey, whatever floats your boat (see what I did there?)

For my wish, I would have opted to meet a panda, sing with Delta Goodrem, or visit the Great Barrier Reef.

Here are some organisations that can help make your dreams come true:

| Organisation | Contact | Eligibility |
|---------------------------------|---|---|
| Dreams2live4 | Ph: 0400 914 375, email: info@dreams2live4.org.au website: www.dreams2live4.com | Adult patients with any of the following... * Metastatic cancer – meaning any cancer which has spread from its original site * Advanced Glioma Stage 3 and 4 * Relapsed lymphoma * Relapsed leukaemia |
| Starlight Children's Foundation | Ph: 1300 727 827 https://starlight.org.au/how-we-help/wishgranting | * seriously ill children and young people aged around 4-21 |
| Make-A-Wish | Ph: 1800 032 260, email: enquiries@makeawish.org.au website: https://www.makeawish.org.au/ | * under 18 at time of application * life-threatening medical condition |

FOMO (fear of missing out)

FOMO is feeling worried that your friends are having fun at an event that you're not going to – often triggered by social media. This can be difficult to deal with because it can make you feel isolated, frustrated, and decrease mental wellbeing.

There are ways to manage it. If you have an important event on which you would like to go to, talk to your specialist to see if you can arrange your appointments around it so that you may be able to attend. This may not always be possible but you

won't know unless you put it out there. Consider voicing your preferences to your parents and/or partner too if they are involved in these decisions. Sometimes you may be able to compromise – you may not be able to go to your formal, but you might still be able to go shopping for your dress; or you may not be able to go to that football match, but maybe your team is coming to visit you anyway.

Nausea and Vomiting

Chemotherapy and radiotherapy-induced nausea and vomiting can be a significant issue for us and can have a substantial negative impact on quality of life. Why? Because being under 30 (or under 50 for radiotherapy) increases the risk of this side effect developing. Other risk factors include:

- chemotherapy with high emetogenicity (potential to make you vomit)
- radiotherapy to the brain, stomach or pelvic area
- radiotherapy treatment area that is larger than 400cm
- being female
- having a previous history of nausea and vomiting unrelated to cancer treatment such as motion sickness.

What can we do about it?

For me, this was a huge issue. I think I can tick off all the risk factors I just mentioned! I ended up in emergency after my first cycle of chemo because I just couldn't get relief with the antiemetic (anti-nausea) tablets I had been sent home with. I spewed all night and into the morning. It was something akin to the worst hangover of my life. After my specialist changed my antiemetics to something stronger (ondansetron wafers) and Mum got me some acupressure wrist bands, it was much more manageable and I avoided further trips to emergency.

- Take antiemetics as prescribed
- Report nausea and vomiting to your doctor, or nurses. If you weren't able to eat because of nausea, say so! If you spew 10 times, say so! If you spewed so many times you lost count, say so! Don't say 'it was okay' if it wasn't
- There are a variety of antiemetics available and your doctor will be able to change them around if your current regime isn't working.

Alternative Management Strategies

These can be used in addition to, or instead of, prescribed antiemetics.

1. Acupressure wrist bands

Cost: \$4.65-\$18.50

Where to access: eBay, chemist or pharmacy

2. Massage

Cost: this depends on the therapist you see. Approximately \$85-\$120 for 60 minute session. If you have private health insurance you may be covered in your policy

Where to access: some hospitals, find an oncology massage therapist
<http://www.oncologymassagetraining.com.au/index.php?content=42>
Massage can also reduce pain, fatigue, and improve mental wellbeing

3. Relaxation/Meditation

Cost: free from the sources mentioned

Where to access: Cancer Council – relaxation CD (call 13 11 20 to order)
- Life Now program in WA (refer to mental Health section for more info)

4. Ginger

Cost: whole root - \$2.88

Tea - \$2.70-\$4.99

Tablets - \$3.49-\$15.65

Where to access: supermarket, chemist or pharmacy

Reminder: Run it by your doctor before taking any herbal supplements as they may interact with your medication.

5. Medicinal cannabis

Cost: seek this information from your doctor

Where to access: can be prescribed by your doctor

Peer Support

A cancer diagnosis can sometimes make you feel isolated. This is particularly pertinent for young people like us, as we are at a stage of life when spending time with friends and fostering good relationships is really important. My fellow cancer patients where I had my treatment were much older than me. Perhaps you can relate to that? This can further exacerbate the feeling of isolation.

Your main source of social support will most likely come from family or friends. However, unless they have had cancer, they cannot fully understand what you are going through. Connecting with other people of a similar age who have/had cancer, or perhaps have experienced a serious illness like cancer, can make you feel more supported...

Sometimes you may not want to talk about cancer or your treatment, and you might just want to spend time with your friends from home. Talk to your specialist and your parents (if they are involved in your treatment), about organising catch-ups with your friends, either in hospital or back home. Remember, if you want to see your friends don't assume that it isn't possible!

Resources

All of these are free!

| Support Service | Description | Delivery | Access |
|--|--|---|---|
| CanTeen | Provides support to young people with cancer aged 12-25 | Face-to-face camps and recreation days, online community | https://www.can-teen.org.au/how-we-help/peer-support-and-programs/ |
| Livewire | Provides support to young people with a serious illness aged 10-20 | Online community, face-to-face programs at some hospitals – arts & crafts, music workshops, multimedia and creative writing activities, celebrity visits... and much more | https://www.livewire.org.au/ |
| Youcan Connect | A virtual 'Youcan' centre for young people to share their stories and connect with others | Online forum | https://youcan.org.au/about |
| The Warwick Cancer Foundation Members Room | A place for young adults aged <40 to share experiences, connect with others, get support and information | Closed online group | Facebook |
| Cancer Council support groups | A safe place to share experiences with others who are also affected by cancer | Face-to-face, over the phone | Ph: 13 11 20 http://supportservices.cancerCouncil.com.au/cancerservicesdirectory/search_onc_all.asp |
| Cancer Council Online Community | Similar to above but sharing experiences through blogs, forums, and online support groups. This is for anyone affected by cancer; cancer patients, survivors, their family & friends | Online | https://onlinecommunity.cancerCouncil.com.au/ |
| Cancer Connect | One on one support | Over the phone | Ph: 13 11 20 |

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|---|--|---|---|
| peer support service | for cancer patients or survivors with a trained volunteer who has had cancer | | http://www.cancer.org.au/about-cancer/patient-support/cancer-connect.html |
| Bowel Cancer Australia peer-to-peer support network | Similar to Cancer Connect | Over the phone, email, or face-to-face | https://www.bowelcanceraustralia.org/buddy |
| Bowel Cancer Forum | Connect with others who can relate to what you're going through | Online | https://www.bowelcanceraustralia.org/online-forum |
| Breast Cancer Network Australia | An online community which provides info and support. There is a group for young people within the network | Online | http://onlinenetwork.bcna.org.au/ |
| Lymphoma Network – Leukaemia Foundation | A network for people affected by lymphoma which facilitates sharing experiences, information, and research news | Closed online group | Facebook http://www.leukaemia.org.au/our-services/education-and-support-programs/disease-specific-facebook-sites |
| ALL Network – Leukaemia Foundation | Same as above but for people with ALL | Closed online group | Facebook |
| Blood Buddies peer support program | One on one support for blood cancer patients with a trained volunteer who has had blood cancer. Matches can be made based on various factors such as diagnosis, age, treatment, or hobbies. Your preferences are taken into account. | Over the phone or email, depending on your preference | Ph: 1800 007 343 http://www.leukaemia.org.au/our-services/blood-buddies-peer-support |
| Limbs 4 Life peer support visits | One on one support for amputees with a trained volunteer who has experienced limb loss | Face-to-face | http://www.limbs4life.org.au/peer-support.html |

| | | | |
|--------------------------|--|--|---|
| Amputees – Limbs 4 Life | Connect with other amputees, access info and resources | Online group | Facebook |
| Gather My Crew | A tool which allows you to delegate practical tasks to your friends/family, such as transport or arranging outings | Online website | https://www.gathermycrew.org/what-is-gather-my-crew/how-it-works/ |
| Stupid Cancer (US based) | A place for young people with cancer aged 15-39 to share their experiences and connect with others | Facebook page, podcasts, app, online community | iTunes store, App Store, http://www.stupidcancer.org/ |

Body Image

Body image is how you perceive or view your physical appearance. In other words, it is your opinion of your physical body. It is common for young people to be focused on how you look and judge yourself against others. The appearance related side effects from cancer treatment can be particularly devastating for our age group as it may make us feel vulnerable or exposed. Some of you may not have been all that comfortable with what you looked like prior to cancer treatment. This would make the appearance related side effects even more difficult to bear.

For me, I didn't find the appearance related changes that I experienced too challenging. These changes were hair loss, a scar on my arm from an incision biopsy, and a portacath implanted in my chest through which my chemo was administered. The port is gone now but a scar remains where it used to be. There were times when I felt down, especially when my eyebrows fell out, but overall I coped okay. Interestingly, I gained a new appreciation and love for my body that I didn't have before. Sure, I looked like Lord Voldemort, but I could walk (depending on how far it was), talk, eat and enjoy food when I wasn't nauseous, shower and dress myself. My alien body was fully functional. I felt that losing my hair was a small price to pay for my life. The odds were very much in my favour but I appreciate that your circumstances and your experience of appearance related changes may be quite different.

These changes in appearance may decrease your confidence and have a significant negative impact on how you feel about yourself. Here are several suggestions to assist you in managing appearance related side effects, mainly regarding hair loss:

Resources

1. **Look Good, Feel Better**

Description: This free service educates cancer patients about how to manage appearance related side effects, such as how to draw on eyebrows, style a turban, and care for your skin. At the end of the session, you will get to take

home a little box of beautiful cosmetic products. I had a lot of fun at the workshop I did, although the other women were a lot older than me.

Delivery: Face-to-face workshops for women, men, and teenagers. If you are unable to attend a workshop, you can order a home-delivered 'confidence kit'. To order the kit, you will need someone in your healthcare team to complete a referral form which is available on the website.

Access: <http://lgfb.org.au/>

2. Camouflage Techniques

Description: Using wigs, turbans, scarves, or hats to disguise hair loss, and clothing or accessories that cover up surgical sites/scarring, prosthetic body parts, and medical devices such as ostomy bags, PICCs or ports. 'Baker boy' style hats (also called 'newsboy' or sailor hats) are perfect because the volume at the crown section gives the illusion that it's full of hair. These are suitable for both guys and girls.

Access:

Wigs

- Wig library at your hospital \$30-\$60
- Call the Cancer Council 13 11 20 to locate a specialist wig shop in your local community. These are more costly than the wigs in the wig library
- If you have private health insurance, wigs may be covered in your policy

Turbans

- wig library at your hospital \$30 approx
- Cancer Council
https://www.cancercouncilshop.org.au/store/shop_turbans \$12-\$89.95
- Louvelle <http://www.louvellewear.com/turban> \$40 + shipping

Hats

- If you don't find anything suitable at your fave shop check out <http://thehatstore.com.au/> which has a large range including 'Baker boy' styles \$25-\$290 + shipping

Eyepatches

- Etsy, online marketplace <https://www.etsy.com/au/> \$6-\$200 approx + shipping
- Follow Jess Van Zeil on Instagram for some inspo

Ostomy Covers

- <http://betweenyouandme.com.au/> \$18-\$44 + shipping
- <http://www.etsy.com/au/> \$8-\$98 approx + shipping

PICC covers

- <https://sleeksleeves.com/> \$20
- <http://www.etsy.com/au/> \$5-\$46 approx + shipping

Prosthetic limbs

- <https://www.mycause.com.au/page/145265/free-3d-printed-hands-and-arms-for-people-in-need>

Contact Mat Bowtell through the link above. He is a prosthetic engineer based in Melbourne providing prosthetic hands and arms **at no cost to the client**. Mat is hoping to add legs to his repertoire in the near future.

3. Wearing attractive clothes

Description: Using the same logic as ‘Look Good, Feel Better’, wearing attractive clothes as well as perfume, cologne or cosmetics can make you feel better about yourself. Similarly, if you have a prosthetic limb, why not get it decorated? Get that tatt you’ve always wanted minus the pain!

Access: Ask your prosthetist and amputee friends!

While it is completely normal for you to have some concerns about your body image, if you are feeling extremely distressed because of any physical changes, please refer back to the Mental Health (p. 4) and Peer Support (p. 9) chapters for some support services. Although these changes are a constant visible reminder that you have cancer, it is important to remember that your health status and medical history are only a part of who you are. There are so many more layers to you, like an onion. You might not recognise the person staring back at you in the mirror, but you are still beautiful.

Relationships

For those in a relationship

Cancer may have a significant impact on your romantic relationships as the dynamics change to that of a patient and carer/co-carer – they can be positive or negative. Cancer is challenging for anyone, but when you are young and in a relationship which might be quite new, it really throws a great big spanner in the works and it can create a significant hurdle in maintaining a relationship. On the flip side, it can bring you closer together than you ever were before and deepen the bond you have. The impacts can develop during treatment and may continue into the post treatment phase.

Other factors that can result from cancer or cancer treatment that may affect intimacy in your romantic relationships are:

| Physical | Psychological |
|--|---|
| Decreased libido | Mood changes |
| Peripheral neuropathy – nerve damage which can affect the genitals causing difficulty in getting aroused, and can affect the hands and feet causing pins and needles or numbness | Communication difficulties. This can occur for a number of reasons. For example, you may feel less connected to your partner or maybe your partner is unsure how to respond |
| Pain | |
| Decreased bladder control | |

For those who are not in a relationship

The world of dating is a minefield for any young person, but is especially challenging for people like us who have or have had cancer. Some challenges that cancer and dating can present are lack of confidence, figuring out when you are ready to start dating again, and deciding how and when to tell your partner about your cancer. You may find it difficult to establish a relationship.

Lack of confidence can arise due to a few different reasons. Body image and coming to terms with changes in appearance, and feeling less attractive because of cancer and the baggage that can come with it like decreased fertility can all contribute. I believe there is someone out there for all of us who is strong enough to help carry our baggage, it is just a matter of finding them. So, don't give up hope if this is something you want.

Figuring out when you are ready to start dating again is very individual. Only you will be able to judge this for yourself. I found that using a dating app was a good way to dip my toes back in the water. I had been in remission for about a year. I decided to be upfront about having had cancer through my written 'bio' and a collage of photos which showed my hair falling out and then growing back. It probably has scared a few people away but not everyone! One of my cancer buddies also used online dating but she preferred to break the news through chatting online. She now has a lovely boyfriend (soon to be husband!!)

Online dating might not appeal to you. There are many other places you could meet a new partner – join a club that interests you, strike up a conversation with an intriguing stranger at your cousin's wedding, or go out dancing with your friends. The possibilities are endless!

Telling your dating partner about your cancer can present a plethora of issues. What do you say? When? How much should you share? Again, this is completely up to you, but it is advisable to do it sooner rather than later, before you and your dating partner become closer to minimise emotional hurt. Don't leave it until your wedding day! If you don't feel you can tell them face-to-face, you could use text, private messaging on social media or email. Remember, embracing the single life is an option too.

You may experience some of the impacts described above for those in a relationship as they can continue into the post treatment phase.

Resources

- Talk to a CanTeen counsellor about how to maintain intimacy in a relationship or manage dating and relationships after cancer <http://canteen.org.au>, ph: 1800 835 932, support@canteen.org.au
- Your Partner & Your Cancer <https://www.canteen.org.au/i-have-cancer/how-cancer-affects-me/relationships/relationships-with-your-partnerboyfriendgirlfriend/>
- Dating when you have cancer <https://www.canteen.org.au/i-have-cancer/how-cancer-affects-me/relationships/dating-when-you-have-cancer/>
- Advice On Sex And Your Cancer Treatment <https://www.canteen.org.au/i-have-cancer/how-cancer-affects-me/relationships/sex/>
- 'The Thing About Cancer' podcast – Episode 2: Sex and Cancer <https://www.cancercouncil.com.au/podcasts/>
- Bring up your concerns to a professional in your health care team

- Ask a peer who has been through or is currently in a similar situation about how they maintained intimacy or how they managed dating and relationships after cancer
- Sexuality & Intimacy <http://www.cancervic.org.au/living-with-cancer/sexuality-cancer>
- Sexuality, intimacy and cancer <https://canceraustralia.gov.au/affected-cancer/living-cancer/managing-emotional-changes/sexuality-intimacy-and-cancer>
- Rekindle – a free online program which aims to address sexual concerns for ≥18 year olds affected by cancer <http://rekindleonline.org.au/>

Questions to Ask

Is it safe for my partner to have sex with me while I'm on treatment?

Can I get pregnant while I'm having treatment?

Can I have unprotected sex on treatment?

Fertility

A potential long term impact of cancer treatment is reduced fertility. This can be really confronting, especially for young people like us. Many of us probably thought that we had plenty of time to start a family... and having children was perhaps something in the very, very distant future (if it was part of our life plan at all). Cancer has fast tracked this and all of a sudden a decision needs to be made *now*.

The degree of damage caused to reproductive organs is dependent on various factors. Some of the factors that increase the risk of infertility are diagnosis type, alkylating agents*, radiation therapy to certain areas of your body, and longer period of treatment which results in a higher total dose of treatment. Being under 30 years old is a protective factor against infertility.

Ask your oncologist or haematologist for a referral to a fertility specialist before you start treatment (if they haven't offered you a referral already). You may have decided not to have children but you might feel differently 10 years from now... and maybe you want to have that safety net of fertility preservation. After discussing your options, you may decide not to go down that path. After undergoing some sort of fertility preservation, you may also decide not to have children later on. It is a really difficult decision to make... but only you can make it. Involve your partner if you have one.

If you have already started cancer treatment, there may be options available to assist you in the future should you have difficulty falling pregnant.

For me, I decided not to preserve my fertility. One of the reasons for this was that it meant that the commencement of chemotherapy would be delayed by about two weeks, which at the time really freaked me out. Sometimes I regret this decision but I know in my heart it was the right one for me. I have been menstruating regularly since completing chemotherapy which gives me some hope that I have the ability to have children without medical assistance.

* Alkylating agents are a type of chemotherapy. Some examples include cyclophosphamide, melphalan, busulfan, carmustine, procarbazine, and cisplatin.

Resources

- IVF Australia – info about fertility preservation, tests, and fertility treatment <http://www.ivf.com.au/>
- 'Maybe Later Baby?' <https://www.canteen.org.au/resource/a-guide-to-fertility-for-young-people-with-cancer/>

Questions to Ask

- What costs are involved (if any)?
- What is the time frame in which the fertility preservation method will be completed?
- What options are available after completing treatment if I have difficulty falling pregnant? (If you choose not to preserve your fertility prior to cancer treatment or you have already started cancer treatment)
- If I'm fertile after completing treatment, how long will I be fertile?
- How will I know if I'm fertile? Are there tests available that assess fertility?
- How have other patients of a similar age to me been affected fertility-wise from the treatment I'm going to have? Have they been able to have children? Did they preserve their fertility? If not, did they need medical intervention to fall pregnant?
- When is it safe for me to fall pregnant after completing treatment?

Life after Diagnosis

Life after diagnosis (AD) and cancer survivorship encompasses all people who currently have or have had cancer, regardless of prognosis. It will look different for everyone, depending on your circumstances.

Education and Work

Consider delaying going back to school, uni/TAFE, or work if you feel like that's what you need. This will give you time to recover and process what you have been through. On the other hand, you may prefer to return as soon as possible to re-establish a sense of normality which is okay too. Whatever workload you choose to take on and whenever you choose to return, listen to your body. Decrease your hours if you feel like you're burning out. Take on more if you feel capable.

For me personally, I decided to take three months off between finishing treatment and going back to work. I worked one morning shift a week when I first went back to work and have slowly increased my hours as my fatigue decreased and I regained strength. I'm now working three days a week. I feel like this approach really helped me.

My friend, on the other hand, who had a much poorer prognosis than me, chose not to return to work AD.

Priorities

You may find your priorities have changed and the work you were doing before cancer no longer interests you. Some cancer survivors feel a responsibility to give back and so they pursue a different career path which reflects this by finding more meaningful work. It is important to remember that you don't owe anything for your survival. You should not feel obliged to raise thousands of dollars, volunteer, or be a cancer advocate. You have to do what's right for you... and this may well be exactly what you were doing before cancer. Everyone's cancer journey is different!

I chose to become an oncology nurse and throw myself into volunteer work with the Leukaemia Foundation. This just made sense to me because I was working as a nurse prior to my diagnosis but I was unsure which specialty I wanted to pursue. Oncology was the perfect fit for me. I can support patients in a better way than if I worked elsewhere. I feel like this is where I can make the greatest difference.

AD, my friend focused on spending time with her loved ones, got married and enjoyed a week away for the honeymoon.

Physical Effects

It is likely going to take a long time to recover from, or come to terms with, the effects of treatment. Your friends and family may expect you to be back to 'normal' (whatever that is). Take things slowly and don't expect too much of yourself. The physical as well as the psychological effects of cancer and cancer treatment are massive.

It is important to attend your follow up appointments throughout survivorship so that if any issues arise, they are detected early.

Psychological Impact

Keep up with your mental health strategies. This is important because mental health issues such as depression and anxiety can be a significant issue for survivors. It is common among survivors to be worried about the cancer returning or perhaps becoming more advanced. This anxiety can be triggered at particular times such as check-ups, or when you experience symptoms that make you think the cancer might be back or spreading further.

Talk to other cancer survivors. They more than likely will be able to relate to the issues you are facing and might have some useful advice in how to manage them (see Peer Support chapter).

Discuss your concerns with your doctor to seek reassurance that what you're experiencing is normal, or is a red flag that requires further investigation.

Resources

- Support and information about life after cancer treatment:
<https://www.canteen.org.au/i-have-cancer/life-after-treatment/>
- Recapture Life – online program delivered via videoconferencing sessions which aims to increase quality of life and prevent distress in adolescents and young adults who have had cancer. The program is facilitated by a counsellor and there will be three to five other young people in the group with you
<https://www.canteen.org.au/research/recapture-life/>

- Cancer Advisor – a reliable information hub which is moderated by Redkite. Content covers a variety of topics including fertility, work and study, and stages of the cancer journey <https://www.canceradvisor.org.au/i-have-cancer/>
- Information for when your cancer can't be cured: <https://www.canteen.org.au/i-have-cancer/if-it-cant-be-cured/>
- Cancer Council Pro Bono Program – free service which assists with drafting wills, debt issues, workplace issues... and much more <https://www.cancercouncil.com.au/31192/get-support/practical-support-services-get-support/legal-financial-support/pac/>
- Living Well After Cancer program – a free three hour face-to-face program run by trained facilitators who have experienced cancer themselves (NSW & ACT) <http://www.cancercouncil.com.au/40724/cancer-information/after-treatment/when-treatment-finishes-after-treatment/living-well-after-cancer-2/>
- ENRICH – free healthy lifestyle program <http://www.cancercouncil.com.au/57676/local-services/metro-sydney-region/services-support-metro-sydney-region/enrich/>
- Work and cancer information: <http://www.cancercouncil.com.au/get-support/work-and-cancer/>
- Cancer Council webinars – free online seminars about various topics related to cancer <http://www.cancercouncil.com.au/get-support/webinars/>
- Wise Employment – an employment agency which provides free services to assist disadvantaged people to find a job <http://www.wiseemployment.com.au/en/home>
- Redkite – provides financial assistance, education and career support for those aged up to 24 <http://www.redkite.org.au/>
- Thinking Ahead: Your Guide to School, Study and Work <https://www.petermac.org/thinking-ahead>

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