



THE CANCER SHITSHOW:

a guide for the
newly diagnosed



NINOX Cancer
Support
Crew





This booklet is produced by Ninox Cancer Support Crew, and contains information specifically for younger adults in their 20s and 30s experiencing a cancer diagnosis in Australia. It does not contain medical advice or diagnostic details on particular cancer types or treatments - that is what your medical team are for.

However, it is full of insights from people your age, who have been through a similar experience. We've shared helpful tips and information we wish we'd known during the whirlwind of the first three months of diagnosis and treatment. It is organised in order of chronological importance - things to know early on and ways to make the whole experience easier, along with a note about what to expect later on.



To keep this booklet short and easy to read, you won't find specific services named; but it's all in the support directory on our website: www.ninoxcsc.com.au

This is also where you should go to connect with people your own age who have similar life experiences.

Lastly, can I just say that it sucks that you're here and need this information, but I'm glad you found us and I hope this helps. You have the resilience to get through this, and on behalf of all NinoxCSC members, we wish you all the best. Get in touch if you need anything - we are here to support you and would love to know how you get on!

Warmly,

Erinna Ford.

Founder, Ninox Cancer Support Crew

Obviously, all information is general and may not apply to your specific circumstances. You should always seek specialist advice, ask lots of questions, and discuss everything with your medical team and other health professionals first.

This booklet would not have been possible without the support and contributions from current NinoxCSC members, the army of proof-readers, fabulous graphic designer Jo Wilson, and financial assistance from ConnectGroups. Thank you!

If you have any questions, contributions for the next edition, or want to get involved, please don't hesitate to get in touch via the website.

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First things first

It's not your fault. Given your age, it is likely that nothing you did or did not do caused your cancer diagnosis. It's a random cell mutation and just plain bad luck, which sucks. Just ask your doctor (again, because I'm sure you already have) and believe them. Now repeat it to yourself regularly. *This is not your fault.*

Fertility

Ask this first. How will this proposed treatment affect my fertility, and what preservation options are available to me? If you've already commenced treatment, there may still be options available to you.

See a specialist. Many fertility clinics can squeeze in appointments for newly diagnosed cancer patients.

What will this cost, now and ongoing? Regardless of which preservation method you choose, ask about the cost for each stage. Are there any options for reduced-fee, bulk-billing or philanthropic funding?

How long will it take? And will any delay for fertility preservation be detrimental to the outcome of your cancer treatment?

It is your choice. Choosing what to do about the future of your fertility is a big decision to make in a rush, especially when you're already overwhelmed. You can take some time to consider your options - talk it over with your intimate partner, support network, or psychologist/counsellor - but ultimately it is your decision.





Finances

Work life. You may be able to continue working during treatment, depending on your job, treatment and how well you recover. At the very least, plan for the possibility that you will need to take some time off and your income may be impacted.

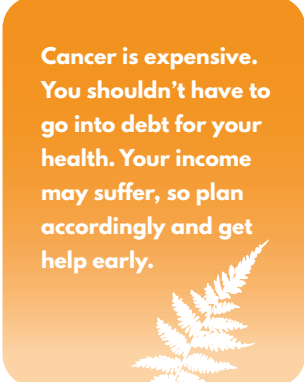
Financial counsellors. Consider booking an appointment with a financial counsellor as soon as possible after diagnosis. They are experts at knowing all possible avenues for financial relief and assistance and, if you give them permission to, they can enquire, fill out the forms, and apply for assistance on your behalf.

Social workers. These wonderful people are often integrated into hospitals and cancer clinics, have a wealth of information, and can also help you apply for practical and financial assistance. Ask your nurses for a referral.



Get in early. Many support services such as financial counsellors have a wait list, so enquire early on. Centrelink applications are often complex and take time to complete and be approved. Call the services you regularly pay money to (bank, electricity etc) and speak to their 'hardship team' *before* you are struggling to afford the bills.

Public vs private system. The decision is yours, based on your financial situation, treatment requirements and personal preference. Have a chat with your medical team, a financial counsellor or social worker, and your private health insurer, and weigh up your options. This can be an ongoing conversation and you may be able to mix it up.


Ask for costs upfront. 'Informed financial consent' means you understand and agree to the costs of all your treatment before starting and throughout treatment. Always ask what everything will cost you (even within the public system), if it can be discounted or if there is a similarly effective but cheaper option, and ask about bulk-billing.




Cancer is expensive. You shouldn't have to go into debt for your health. Your income may suffer, so plan accordingly and get help early.



“Can it be bulk billed?” This should become a regular question you ask of doctors, nurses and clinic staff. Some scans, pathology, and treatments that normally require out-of-pocket payments can be bulk-billed or reduced in cost (i.e. you don’t pay the full amount) - but it’s not the default. Don’t be embarrassed by asking - they may not think of it if you don’t ask.



Fee caps. The PBS Safety Net and Medicare Safety Nets can help reduce the cost of medication and out-of-pocket medical fees. You may need to register, and keep track of your medical expenses, so definitely speak to a social worker, financial counsellor, pharmacist, nurses or your local Medicare office.



Accept the money. Look, we know you’re an independent adult who thinks they’ll be fine financially. Sure there are people worse off than you. But it’s not a competition and you are going through a shit time, so if the government, a support service or trusted source offers to help you financially, take it (unless it’s drug money, then maybe reconsider).

Prove it. Your employer or school or Centrelink may request a medical certificate confirming your diagnosis and treatment. While annoying (because who would make this shit up?!) it is simple enough to get - just ask your doctor or nurses. You can get them updated regularly, and they can also be used to support a request for reduced hours, extended deadlines, or a work-from-home arrangement.





Telling people

You control your story. What you say, how much or little you share, and who you tell, is completely up to you. You can place boundaries on who is told; you don't have to share if you don't want to, and people should respect your privacy.

Telling work or school. You don't have to tell your employer unless your diagnosis, treatment or side effects may affect your ability to work safely. But telling your employer or educators can help facilitate flexible arrangements. You may want and be able to continue at the same capacity, but expect, at the very least, to need some extra time off for appointments.

Managing emotions. You are not responsible for managing the emotions of other adults. You should not have to comfort someone else when discussing your own cancer experience. Suggest they talk to a counsellor. Look after yourself first.

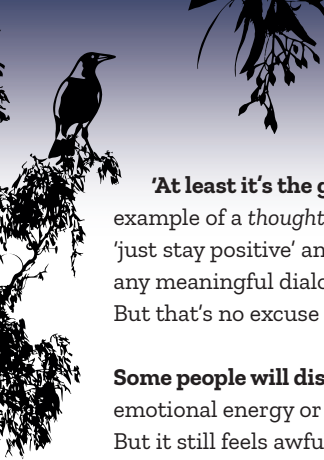
Prepare for weird comments. You'll likely hear opinions on what caused it, about distant relatives who died of a dissimilar cancer, of random unproven herbal concoctions, and how you're suddenly 'an inspiration'. How you respond is up to you - eye rolling, saying "not helpful", or asking about their medical qualifications are some suggestions.

What did you do...? Cancer that randomly occurs in otherwise healthy individuals scares the crap out of some people. They will blame you for your diagnosis - eg you got a vaccine, eat an unrestricted diet, don't believe in god, or have unresolved emotional baggage - things that, of course, will not apply to them. They are terrified of this happening to them. But they are acting like arseholes, so don't feel bad about treating them accordingly.



Our booklet
'The Shitshow
Companion' offers
family and friends
insight into the
realities of a cancer
diagnosis and tips
on how to provide
support. It is
available for free
on our website.





'At least it's the good cancer.' There is no such thing - they're all shit. But this is an example of a *thought-terminating cliché* - along with 'everything happens for a reason', 'just stay positive' and other unhelpful optimistic statements. It's a flippant way to end any meaningful dialogue and is used by people who feel uncomfortable with the topic. But that's no excuse for minimising your worries or the seriousness of the situation.

Some people will disappear. It's not you - they clearly don't have the emotional energy or maturity to give you the support you need. But it still feels awful and is really disappointing when it happens.



Grief tourists. On the flip side, some people will suddenly reappear in your life or want to get heavily involved. Some will be genuine in their desire to support you, whereas others will be there just for the public praise - the dead giveaway will be how they respond when you set boundaries and if they stay for the long haul.

Treatment life

Remember to breathe. Finding a calm, still, way to centre yourself during stressful and uncomfortable situations is a really valuable skill to have during scans and treatment. Downloading a meditation app can be a good first step.

Be patient. Everything takes a lot longer than expected so bring your devices (and headphones, please, for the sanity of everyone around you!), books, water and snacks. When checking in, it's perfectly acceptable to ask for an estimated wait time, and if you're waiting for longer than that, it is okay to ask again.

Ask questions. You're not annoying. It is your right to know about and understand what treatments you are having and why. If you don't understand, ask for it to be explained in a different way or by a different person, so you can give fully-informed consent (nurses are great for this).

Take notes. A diagnosis means being thrust into the unfamiliar world of medical terminology, and treatment can be a shock. You might miss important details and it's likely you won't remember everything. Keep a dedicated notebook for writing notes, your questions and the answers received. Take a trusted support person with you to appointments - they can take the notes and keep track.

What's your number? Ask your doctor for the phone number you can call with follow-up questions. This is especially important for after appointments that discuss diagnosis, treatment or other decisions you need to make.

Speak up. You are your own best advocate. You should trust your team implicitly, but if you are uncomfortable or something doesn't work for you or doesn't feel right, tell someone, ask questions and talk about options. This includes finding ways to counteract any side effects from treatment, questioning a change in routine, or having difficulties with a member of staff. Trust yourself and don't suffer in silence.

Be nice. You will be seeing a lot of your nurses, ward clerks and admin staff. Be nice to them, learn their names, chat about Netflix shows, and bring treats. You should receive a high level of care regardless and you're bound to have bad days, but it will make everyone's experience a lot easier.

Second opinions. While doctors have the knowledge and experience, you are an individual and ultimately in control of your treatment choices. You have the right to ask questions and to seek a second opinion if you're not happy. Although you might be worried that this will insult the original physician, if they are a professional it should not impact the level of care you receive.



If you attend appointments alone at any point, you can request that a nurse (or other support staff) accompany you, to take notes, explain jargon and provide emotional support.

Prepare to vomit. You may never experience nausea or vomiting as a side effect. But, just in case, grab a couple of vomit bags from your clinic nurses and stash them in your bag, your car and bedside table. Don't hesitate to take anti-nausea meds if they are prescribed and recommended.

Talk shit with your nurses. Are you constipated, or have diarrhoea and can't trust a fart? How about in pain, itchy, nauseated or can't sleep? Your nurses have heard and seen it all before, so trust them, tell them, and they will likely have ways to make it better.





What can be said during cannulation, as well as during sex?

“If we rub it a bit, it might pop up.”

“Pump your hand a few times for me.”

“Let’s try a different angle.”

“Is it in already? I didn’t feel a thing.”

“You’re the best I’ve ever had.”



Juicy veins. Your veins will likely be in high demand for blood tests or cannulation. To make them more accessible for the nurse and thus easier on you, try these tricks: drink plenty of water in the 24 hours beforehand; warm up your arm or hand by wearing a jumper, gloves or using a heat pack; drop your arm down low to help promote blood flow; and request a small needle.

Blood on tap. If you are offered a Port, PICC line or similar, ask questions and seriously consider one. They can make it much easier to take blood and receive infusions, and will help save your skin and veins from the rigours of treatment and cannulation attempts. Many people find them invaluable, but they may have some downsides for your lifestyle, so choose what’s best for you.

Tattoos, nudity and bondage. For radiation therapy, they need ways to consistently target the same area each time. This may require teeny tiny tattoos, sometimes on skin you’d usually keep covered up, and a tight-fitting mask that keeps you in place. Talk to your technicians, trust they’ve seen it all before and will respect your dignity, and remember to breathe.

Immunosuppression. You can ask for the result of each blood test and learn about your white cell count, platelets, neutrophils and other important markers. These indicate if you are immunosuppressed or at risk of infection, and if you need to take extra precautions to stay well - your nurses can give you all that information.



What happens after-hours. Ask for an after-hours phone number for when you are worried or have questions (it might be the hospital oncology ward). Don't hesitate to call; there are no stupid questions. For the possibility that you may need to attend the emergency department, many clinics have an actual 'cancer card' that you present upon arrival. It indicates your possible compromised immune system and should enable a quicker admission, ideally isolated away from other patients.



Empower your caregiver. When you're really unwell you may not be in the best position to speak for yourself. Allow your willing partner, trusted friend or other caregiver to advocate on your behalf. This can be important to ensure you get the best and correct care in an emergency situation or even during routine treatment. Include them early, inform the medical team of your wishes, and if necessary you can formalise it with an Enduring Power of Guardianship.

I almost forgot... Chemo brain, or chemo fog, is one possible side effect from treatment. It's hard to describe but your mind goes fuzzy, your ability to concentrate declines, and your memory is noticeably different. Its effects may only be short-term, or may persist beyond finishing treatment. Be patient, write everything down to help your memory, and tell your medical team.


Brain waves

Get therapy. Talking with a mental health professional can help ease the emotional burden and offer useful coping techniques. You can access counselling through many support services or ask your clinic for a referral to a psycho-oncology specialist. Get help early and keep going longer than you think you need it.

Keep it up. Continuing your hobbies or starting a new one will keep your brain active. Seeing your loved ones and having a laugh will also feed your soul and give you something to look forward to when you're feeling low.

Complementary therapies. Having reiki, massage, reflexology or other therapies won't cure your cancer, but they may make you feel better and more in control. Seek recommendations from your cancer team, and let therapists know about your treatment so they can plan and adjust accordingly (eg adjusting massage intensity so you don't bruise when your platelets are low).





Compromise. You'll likely need to juggle your energy levels to deal with treatment and side effects along with the other things you need and want to do. Being unwell can feel like a full time job. It's okay to be sad about missing out on things you enjoy, or not keeping up like you did before. Get help where you can and be kind to yourself - you're doing the best you can.

Positivity isn't a cure. There's going to be shit days, and that's okay. You don't need to 'stay positive' or 'stay strong' all the time. Ignore the cancer-inspiration-porn on social media. Having other things to focus on, like family or hobbies or long term goals, can help get you through - but so can helpful coping strategies from a trained mental health specialist.

Survivor's guilt. Try not to compare your cancer experience as 'easier' than other people's and that means you have nothing to complain about. Everyone's experience is different - yours is valid and you are allowed to feel shit sometimes. Have a chat with your therapist and find the best ways for you to work through it.

Caring for the caregiver. It can be tough caring for someone who is really unwell, so encourage the people closest to you to look after themselves and access the practical and emotional support available to carers.

You are not alone

You are not a burden. The people who you love, love you too. Everyone goes through tough times, and it's just currently your turn. Let them love on you and fuss just a little, like you'd do for them.

Accept the help. It can be hard to rely on others, but if you have people and services who can support you in the ways you need, allow them to. As an independent person it can be humbling and uncomfortable to receive help. But services are literally there to help people going through a shit time, like you are, so just say yes.

“Brave is just another word for ‘quietly scared shitless’”

@THANKSCANCER
ON TWITTER



Hold the line. Even when accepting help from others, you are still allowed to say no and expect people to respect your limits. If people are overstepping, you can push back and reinforce your boundaries.

Be flexible. You can still see your friends and family - everyone might just need to be flexible with how, where, and for how long. If your immune system is low, maybe a video call; or if you're exhausted, a brief visit may be best. You are in control and can cut it short or change your mind at any time.

Cancer with children. Involve your willing family and friends to help with childcare, during and after treatment. Seek out the services that help and support children to process and cope when a parent is unwell.

Make friends. It is also okay to say hello to fellow cancer peeps, especially those of a similar age. If you're shy, ask the nurses or send your caregiver over for a brief hello... although the waiting room might be the best place instead of when their curtains are closed or they've got their head in a vomit bag.

Support services available. There are a lot of services available (I'm guessing you've already received a bunch of booklets and pamphlets, right?). Finding the support that suits your specific needs might be a bit more of a challenge though. Talk to other cancer patients or your health team to find solutions that suit you.

Peer connection. Regardless of how amazing and supportive your friends and family are, it can be reassuring to meet other people your age who have been through a similar cancer experience. It can normalise your experience, to know that you are not alone, and give you some idea of what to expect in future. Reach out and try it, even if it's just once.

Ninox Cancer Support Crew hosts monthly events in Perth for adults in their 20s and 30s with any cancer diagnosis.

You're welcome to attend.



Nutrition

Sugar isn't the devil. Ignore anyone who tells you that 'sugar feeds cancer cells' (they don't know what they are talking about). Eat the cake, and tell them to mind their own business.

What's your diet like? Treatment can affect your appetite and taste buds, so when you feel like eating, eat what you feel like. It isn't recommended to drastically change or restrict your diet as cancer treatment is already a big shock to the system. Obviously you want to include a majority of healthy food most of the time, but it's okay to eat what tastes good.

I'm not hungry. You need to eat so your body can cope with treatment. If you can't face three big meals, try preparing a platter of options, and snack like a toddler throughout the day. Making fresh juices can be an easy way to digest essential vitamins and nutrients. If you're really struggling, seek the guidance of a specialist dietitian (ask your clinic for a referral).

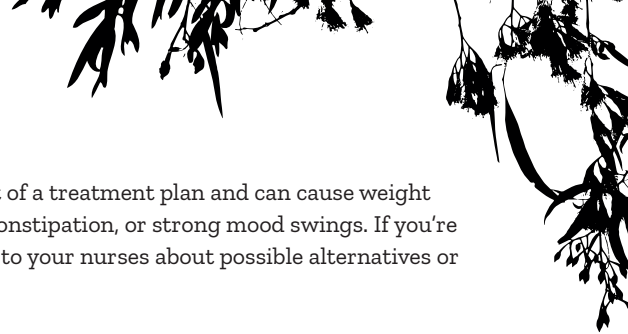
Stay hydrated. Drinking plenty of water will help you to feel better and keep your system flowing. Add some electrolytes, cordial or other flavouring to make it easier to swallow. Sucking on ice chips or drinking herbal teas are other options. Be aware that coffee, some energy drinks, soft drinks and loaded teas can contain caffeine which may make your heart race uncomfortably.

Pill popping. Before you take any herbal or vitamin supplements, your medical team needs to know, because some over-the-counter pills or herbal remedies can negatively interact with cancer treatments and medications.

Body health

Exercise. You don't have to run a marathon, but continuing some exercise during treatment may help reduce the severity of physical and mental side effects. You may need to modify slightly to compensate for side effects and a low immune system. Seek out specialist programs, exercise physiologists and physiotherapists who are trained in exercise during and after cancer treatment.





On the 'roids. Steroids can form part of a treatment plan and can cause weight gain, insomnia, increased appetite, constipation, or strong mood swings. If you're struggling with any side effects, talk to your nurses about possible alternatives or ways to soften the effects.

Hair. Not everyone loses their hair. But if you do, the choice to shave, wear a wig, flaunt a bandanna or scarf, or not, is completely up to you - there are lots of fabulous options whatever you choose. It is important to protect your noggin from the sun; and a beanie will keep your body warmer at night. Also, be prepared that you may lose hair all over... yes, all over.

Sun care. Ask whether your treatment will make you more susceptible to sunburn and take appropriate action, even in winter - sunscreen, hats, sunglasses, long sleeved shirts.

Intimacy

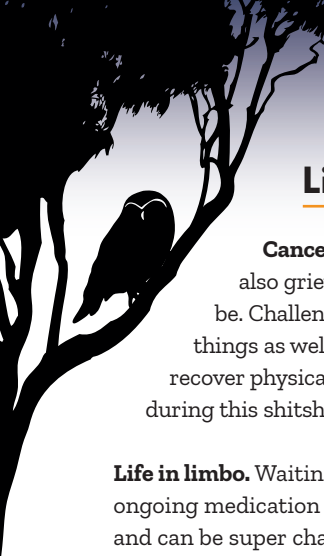
Sexy times. There may be times you will be unexpectedly and ridiculously horny. Other times you won't want to be touched at all. Communicate clearly with your partner, and it should go without saying that you should never be pressured into having sex.

Lube is your friend. Some treatments can dry out your skin and other areas. Find a gentle moisturiser for your skin, and use lube liberally during sex (and obviously stop if it hurts).

Toxic love. It is possible for chemotherapy and other medicines to be transferred via bodily fluids - including during sex. Learn how to protect yourself and your partner, and ask your medical team if it's something that applies to you.

Oh baby baby. It is possible to conceive during cancer treatment, which can possibly cause complications. Talk to your medical team about the risk and the need to use protection until they say it's safe.





Life after

Cancer is trauma. Diagnosis and treatment can be tough. But, you may also grieve the loss of your innocence and the carefree person you used to be. Challenging memories and emotions may be triggered by really random things as well as the more obvious ones too. It will take guidance and time to recover physically, mentally and emotionally after everything that's happened during this shitshow. Be kind to yourself and get help.

Life in limbo. Waiting for results, being on a watch-and-wait schedule, or having ongoing medication can make you feel that your life is on hold. This is completely valid and can be super challenging. Talk to your medical team and seek regular help from a trained mental health professional.

See you in three months. After the whirlwind of diagnosis and the conveyor belt of treatment, it can be jarring to be sent off into the world without supervision. You may still feel sick, exhausted, and shell-shocked. If you are worried about anything between appointments or scans, you can still ring your clinic to ask questions of the nurses or doctor.

It may be harder emotionally. Many people find the period after treatment to be emotionally challenging, when you've finally got time and brain space to start coming to terms with what has happened. As you near the end of treatment seek help from your mental health therapist to support you through this transition.

Introducing scanxiety. Feeling particularly anxious in the lead up to a checkup scan or while waiting for the results? This is called 'scanxiety' and it's totes common. Find ways to distract yourself, centre your emotions, and schedule your psychologist and self-care activities for around this time in preparation.

Anniversaries. Some people mark the date of their diagnosis, when they ended treatment, got their first clear scan, or another treatment milestone. Whether you choose to do something or not is up to you. But at the very least, have cake.

Returning to work or study. It is perfectly reasonable to need time to recover after finishing treatment. Get a supportive medical certificate and, if you're able, negotiate with work or study to have a little bit of time off just to recover. Also consider part-time options as you ease back into it.

It will take time. Friends and family may want to celebrate the end of your treatment, to move on and 'get back to normal'. It's okay to feel hesitant so don't feel pressured and go at your own pace.

Rebuilding. It may take a year or two to trust your body again and to feel like the jigsaw of your life is fitting back together. Don't be surprised if it also looks and feels a bit different than before.

The gift that keeps on giving. Unfortunately some side effects may continue after treatment ends, while some may not appear until months or years later. Get the list of possible long effects from your specialist, share it with your trusted GP and check in regularly. Tell your health team about anything you are worried about regardless of how random and tiresome it may seem.

Staying well. The best ways to keep yourself healthy after treatment are the things you probably already know: eating balanced healthy meals; wearing sunscreen; drinking alcohol in moderation; moving your body regularly; not smoking; and by attending your recommended regular checks and scans.

A cancer diagnosis does not define you. It is part of your life, but is not the sum of who you are or what you will be.

Despite how it feels right now, this is only temporary and you have the resilience to get through it.

♡ Best wishes



Check out the directory
on our website for a
heap of helpful resources
www.ninoxcsc.com.au





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