



THE SHITSHOW COMPANION:

how to be a good friend
during cancer



NINOX Cancer
Support
Crew





Receiving a cancer diagnosis is one of the most shocking things that can happen to a person, especially when they are a younger adult and seem perfectly healthy. The support provided by friends and family has a huge impact on how well they cope with treatment and side effects and all other areas of their lives. But it's a learned skill - so how do you know what to say, what to do, or what support is needed? That is why this booklet exists!

Ninox Cancer Support Crew is for adults in their 20s and 30s with any cancer diagnosis in Australia. This booklet contains insight from members and their support network who have been there before. Everyone's experience is different, so not everything in this booklet will apply to your friend. Remember that you know them best, and if in doubt, just treat them the same as you did before their cancer status - just with extra doses of empathy, patience and love.



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 find your friend a copy of 'The Cancer Shitshow: a guide for the newly diagnosed'.

It sucks that your friend has cancer and that you need this information, but you're doing a great job and I hope this helps a little.

Warmly,
Erinna Ford.
Founder, Ninox Cancer Support Crew

Obviously, all information is general and may not apply to you or your friend's specific circumstances. Always seek specialist advice and never make decisions that would affect the person with the diagnosis without involving them - even if you mean it to be a surprise.

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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

This is nobody's fault. It is highly likely that our cancer was not caused by anything we did or did not do. It is a random cell mutation and plain bad luck. To suggest otherwise will be distressing, unnecessary, and downright rude.

Your role should you choose to accept it. We simply want you to be our friend, to keep in touch, boost our morale and provide some normality. If you're able to provide extra support in the ways we need it, fabulous. But by being a good friend, you're already helping us a lot through this tough time.


The basics


Cancer isn't contagious. You can't catch it through proximity or touch, so if we are friends that hug, don't stop now.

Manage your own emotions. Hearing of a cancer diagnosis is upsetting - we get it. However, don't let your own fears overwhelm us when we need your support. Showing emotion is fine (being cheerful at the news would be weird!), but hold off on your deep cries and fearful speculation for when we aren't there. It would be terribly inappropriate if we end up comforting you instead.

Life will change. We're not even sure how just yet, but our life may look a bit different for a while. We may not be able to work or socialise as much, we may start to look a bit different, and our priorities will possibly change, at least in the short term.

Just ask us.
Want to know more about
our diagnosis? Ask us.
What's going on with
treatment or side effects?
Ask us.
Not sure if we want to 'talk
about it' or not?
Just ask us.





Treat us the same. You know how you acted six months ago, before cancer was on the radar? Yeah, like that - treat us like that, with extra doses of empathy, patience and love. We are still the same person with the same boundaries, the same quirky habits and sense of humour - we're just going through a rough time and will be desperate for some normality.

Our story belongs to us. If we have chosen to tell you about our diagnosis or treatment, that is for your ears alone. Don't share it with anyone else, even if you think they already know, unless we give you permission to do so - even then only share the bits we have agreed to.

Keep in touch. You don't know what to say or how to act, feel awkward or don't want to bother us? We feel exactly the same! So even if it's just a quick call, text, email or DM, please keep in touch - it really means a lot to know you care and haven't forgotten us. But also, please don't be offended if we don't get back to you straight away - there's a lot going on.

Be flexible and patient. Cancer and treatment is overwhelming - combined with dealing with the emotional burden and physical side effects, we are exhausted. So if we need to change or cancel planes for any reason, please be flexible and have patience.

Cancer is trauma. Having a cancer diagnosis can mean the loss of innocence and the carefree person that used to exist. We likely have to suddenly make decisions that will affect our future. Treatment itself can be hard and traumatic, both physically, mentally and emotionally. Be patient and be kind.

Mental health care is vital. Encourage us to seek the services of mental health professionals - during treatment and also into recovery. We should feel no shame or embarrassment for seeking help, but unfortunately it still happens. You can normalise it by talking about it.

The support you provide is invaluable. By providing empathy, comfort and support - *by being our friend* - you are helping us get through one of the toughest experiences of our lives. It might be rough for a while, for all of us, but know that we really appreciate having you by our side.



What is happening

The weight of cancer. A cancer diagnosis can be a heavy burden. If you're fortunate to have not been through something similar, it's hard to know the invasive impact a cancer diagnosis can have on your life - it should not be trivialised. Some common concerns and issues can include:



- » impact on fertility
- » interruptions to work and study
- » how to tell everyone
- » who to tell
- » maintaining some privacy
- » feeling like a burden
- » being left behind socially
- » paused career progression
- » impact on our children
- » reduced income
- » affording treatment
- » affording regular bills

- » impact on dating and intimacy
- » feeling isolated and lonely
- » managing side effects
- » staying well while immunocompromised
- » feeling shallow for worrying about changing appearance
- » grief and mourning loss of innocence
- » struggling with anxiety and depression
- » reduced financial security
- » fear of relapse and dying
- » uncertainty about the future

Fighting the cancer 'battle'. Cancer is a biological disease. The success of treatment is based on how our body and the cancer responds to it. It unfortunately has nothing to do with our emotional positivity and strength, or tenacity or will to live. But continue to encourage us and lift our spirits, as it will make this experience easier to bear.

Conveyor belt. Receiving a diagnosis is akin to being sat down onto a conveyor belt that takes you through the stops of a scary unfamiliar landscape. There are a lot of appointments, new words, and big decisions to be made. Things often happen quickly, are super confusing and overwhelming, and by the time you've found your bearings, you're let off at the other side without supervision.

Different treatment types. Common treatments include chemotherapy infusions or tablets, radiotherapy, immunotherapy and surgery. There are many others, in addition to heaps of cancer subtypes and other variables that influence which treatments are used. Just ask us what our current treatment plans are, and if you want to know more, approach trusted sources (nurses, cancer centres, support services etc).

It's not fun. Ignore the cancer-inspiration-porn on social media. As part of diagnosis and treatment we may be poked, prodded, stabbed, cut, restrained, stitched, tattooed, waxed, filled with toxic chemicals, and regularly asked about our bowel movements. It's not enjoyable and it hurts.

It's only surgery. If surgery is able to fully remove the cancer without the need for further treatment it may still have a major impact on our life, with many emotional and physical challenges. So, don't be an arse and minimise it by saying 'it's only surgery'.

Fertility. Some treatments can impact a person's fertility and ability to have children. While there are preservation options available, this may not be a possibility for everyone due to timing, costs, or personal choice. Even if we had previously declared our child-free plans, having the choice ripped away from us is still upsetting. It's rude to ask about, so don't (unless we bring it up first).

Body adjustments. Surgery, side effects and treatment can change the way our body looks and feels. This can be a shock and it's not shallow if we mourn our appearance and take time to be at peace with it. Please avoid flippant remarks (eg. we know the hair will grow back; cancer weight loss is not to be applauded; and it's not a 'free boob job' ffs).

What day is it? Chemo brain, or chemo fog, is one possible side effect from chemotherapy. The mind goes fuzzy, the ability to concentrate declines, and memory is noticeably different. It may only be short-term, or may persist beyond finishing treatment. So if we space out, forget about a date, or can't recall a conversation, try not to be too upset - it's possible we can't help it.

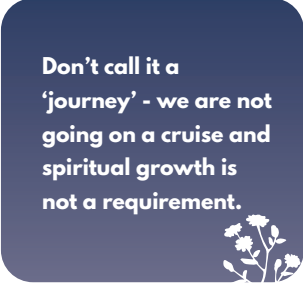
Strapped for cash. Understand that our finances will likely be impacted - we may have to stop work, or reduce our hours. And cancer is expensive - even going through the public system will cost money (and not just the parking costs!).

Possible side effects of treatment. There are a broad range of side effects, which depend on the person and the treatment type they receive, but commonly can include:



Let's talk about it

I don't know what to say. That's okay - just say that. Another acceptable response is 'I'm here for you'. It's more hurtful to feel ignored because you're worrying about what to say, than to have an awkward but caring conversation.



Don't call it a 'journey' - we are not going on a cruise and spiritual growth is not a requirement.

Swearing is acceptable. Some suggestions include "this is really shit" or "stupid fucking cancer".

Tell positive stories. For some reason, when someone has a cancer diagnosis, the go-to stories are those where the person died of a similar cancer. We're already aware of the possibility, so instead please tell us optimistic stories where people survived and thrived afterwards.

It's okay to laugh. If we are making a joke about our diagnosis, treatment, side effects, or anything else, it is okay to laugh with us - just be warned that our humor might be a bit darker than usual.

Life outside cancer. Continue to chat to us about work, dating, your family, and hobbies. We still care about you and some normalcy can be wonderful. If you're not sure, just ask.

Avoid thought-terminating cliches. By their very definition, these phrases are designed to discourage conversation. They may seem optimistic, but are entirely unhelpful, and make it clear that you do not want to hear more. They can feel like a slap in the face and it's likely we won't confide in you again.

Examples include:

- *Everything happens for a reason*
- *It could be worse*
- *Just stay positive*
- *It's part of God's plan*
- *You're so brave/inspiring*

At least it's the good cancer. There is no such thing - they're all shit.

Sit with discomfort. It would mean a great deal to us if you can learn to be okay with talking or hearing about the uncomfortable topics that we now have to face. Even though it's a sign of maturity, growth and strength, we also know it's challenging, especially if you've never had to deal with it before.



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

@THANKSCANCER
ON TWITTER



We know you can't fix it. One of the best things you can do is sit with us while we are upset, and learn to be okay with not knowing the answers or being able to solve it. Let us have a bit of a bitch about it and then ask if we want to be distracted.

Positivity isn't a cure. Of course we are hopeful that treatment is successful, and having a positive mindset might keep us motivated. But expectations that we stay 'positive' or 'strong' all the time are exhausting and won't make much of a difference to our biological treatment response.

How are you? We get pretty sick of this question being asked, especially when it's out of pity or social obligation and not because they actually want to hear a truthful answer. It's tiring and disheartening to have to pretend everything is 'fine'. What to say instead: 'It's great to see you. Do you want to talk about it?'

You look awful. Unless it's something we can fix or change (like a stained top), avoid commenting on our physical appearance including our hair, weight gain or loss, and scars. Note: not all people 'look sick' when they have cancer or lose their hair during treatment.

It'll grow back. While it may seem vain to mourn the loss of hair, remember this wasn't our first choice of hairstyle. Plus, losing our hair may make us look more like a 'cancer patient'. It is a big deal so try not to minimise our feelings about it. Instead, show us awesome hats, wigs or scarves that would suit us, and if we choose to flaunt the bald look, confirm that we look awesome.

Have you tried..? Unless we bring it up first, don't question our treatment choices or push alternative therapies or spiritual miracles. There's nothing wrong with trusting experienced medical professionals and decades of science.

When to share wisdom. Avoid giving treatment advice, even if you've had cancer yourself or work in the health sector. However, if you are in-the-know and have tips to reduce the severity of side effects, ask first if we want to hear them. And remember that it's not a competition on who's had it worse.

You're not a psychologist. You are not expected to bear the burden of our mental health. It is okay to request that we not trauma-dump onto you, and to admit that you're not equipped to help with certain topics. Support us while we seek help from a trained mental health professional or service



Social life

If you don't know how to act... that's okay. No one really does, so just be your usual awesome self.

There will be good days. It's likely we won't feel sick all the time and will have days where we want to do things as normal. Sometimes it's predictable and we will try to forward-plan accordingly. Other times it may be a complete surprise and we'll want to make the most of it with impromptu plans.

A low or non-existent immune system is a side effect of some treatments. We may get dangerously unwell from otherwise low risk germs. Stay away if you or someone you're close to is unwell.



Still invite us. Even if we can't attend an event, we will still appreciate the invite. It hurts to find out (especially via socials) that we've been intentionally left out and left behind.

Cancellations. Continue to make plans, but understand that we may need to cancel or change them at the last minute because of appointments or side effects. We don't want to cancel, and we will already be upset about it, so please have empathy.

Give plenty of notice. Let us know that you're wanting to visit us - best not to turn up unannounced. And if we're not feeling up to having visitors, don't take offence if we ask you to stay away.

Flying visits. Cancer and treatment is exhausting, so keep any visits short and sweet. At the hospital, if a nurse or doctor turns up, step outside the room or take your leave - don't linger or listen in.

Reconsider flamboyant surprises - especially in public. We are likely already self-conscious and don't want more attention. Plus, after the shock of our diagnosis, surprises probably aren't so fun anymore.

Social media etiquette. Avoid tagging us in pictures or in the comments of any cancer related stories or news that you find. Ask us first if we want to receive them, and even then best share it as a direct message instead. Funny memes and animal videos are always welcome though!

Don't smoke. We know smoking can cause cancer, so why would you impose that on us? This also includes having a quick ciggie or vape before you see us. We will be extra sensitive to smelling it and it's vile.

Cancer buddies. It can be reassuring to meet people our age who have been through a similar experience and speak the same language. We are not replacing you, merely adding to our friendship group.

Work and school

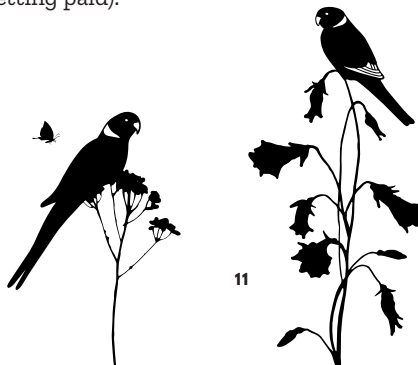
We're still here. Not everyone who has cancer treatment will stop studying or working for the duration. We may not be able to afford to have long periods of leave - it can be bad for our career opportunities and for our bank balance. Plus keeping to a normal routine and having non-cancer interactions is good for our brain and morale.

Study buddies. If you are in the same classes, ways you can help include recording the lectures and maybe buddying up for assignments. Teachers can help with accommodating extension requests, making it easy to access lecture notes and recordings, and providing a little more one-on-one support if possible.

Let's make it work. While we may continue to work, we will likely need some time off for appointments and whatever treatment and recovery is prescribed. We know it's inconvenient for everyone involved, so let's brainstorm how to make it work.

Find flexibility. Study: can we defer a unit, deadline or assignment without it affecting our overall grade? Work: can we work at home or switch to part time hours? Let's find ways that will allow us to work around treatment and side effects, while still contributing (and getting paid).

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



Home life

Keep it clean. Some treatments can impact the immune system and make us more susceptible to infection. If we live together, you might want to be extra aware of disinfecting and keeping the house clean and germs (and germ-y people) away.

What's your diet like? Treatment can affect the appetite and taste buds, so it's important we eat what tastes good when we feel like it. Drastically changing diet is not recommended as cancer treatment is already a big shock to the system. Obviously, we want to include a majority of healthy food, but it's okay for us to eat what tastes good.

Sugar isn't the devil. Don't even start on the misinformed topic of sugar feeding cancer cell growth (it's nonsense). Plus we are going through a tough time, so why would you deny us cake?

Snack like a toddler. Weight loss during cancer treatment can be detrimental. But it can be a struggle to eat three big meals every day. You can help by preparing a platter of options, and let us snack throughout the day. Making fresh juices can be an easy way to digest essential vitamins and nutrients. If we're really struggling, nutritionists can provide options (ask the cancer clinic for a referral).

For intimate partners

Don't touch me. Due to treatment side effects and trauma, combined with impacts to body changes and self esteem, sex might not be on the cards for a while and should not be forced (ever).

On the other hand... Sometimes we may be feeling frisky at the most unexpected times. But treatment side effects can include skin sensitivity and dryness, so lube it up, take it gentle, and stop if we tell you it's uncomfortable or not pleasurable.

Toxic love. Some treatment drugs, such as chemotherapy, can make body fluids toxic, which can be transferred during sex. Check with us (and the clinic nurses) whether this applies and the ways to keep us both safe.

Use protection. Becoming pregnant during cancer treatment is possible, but may not have the best outcome. This is another topic for the clinic nurses: ask about the risk, and use contraception.



Get professional help. It can be hard watching the person you love going through a rough time, and it may be hard on your relationship too. It's a sign of strength to seek and accept help from specialist support services and trained mental health professionals. We want you to be okay.

How to help

Take our mind off it. Bring over a movie, snacks and good conversation (make sure the movie doesn't involve cancer though!). If we are feeling up to it, take us out for an activity we love and let us forget all about cancer, just for a little bit.

Tell me how I can help... but it's likely we won't. It's common to already feel like a burden to our family and friends, so we may not ask for help. Learn the ways we need the help, tell us what you plan to do, and then follow through.

Do some research... We suddenly need to upskill in all things cancer and how to navigate the medical system, on top of the emotional overwhelm and the usual life admin. If you can look into topics that we need help with, such as what legitimate and relevant support services are available, that can be a great help.

...but not too much. Don't go down the rabbit hole of internet conspiracy theories. If you start believing that doctors and big pharma are hiding the cure for cancer, you've gone too far.

Financial burden. We don't expect our friends to help us financially - but you can help by looking into what financial support or assistance is available and how to access it.

A note on fundraisers. It's a very sweet thought, but please ask us first! We won't appreciate having our name and story spread around the internet and social media without our permission. And it might have implications for our income tax or any government support payments we are receiving.

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



Practical ways to help

- **Attending appointments.** Take notes and provide emotional support. Run for coffee, food and prescriptions. It can be boring so bring a book or device and headphones.
- **Treatment taxi.** If it's a quick appointment or infection control doesn't allow a support person, drop us off, pick us up later and take us out for a coffee and debrief.
- **Food shopping.** Find out what we need and, if you're dropping it off or ordering online for delivery, ask us what time suits and let us know when to expect it.
- **Look after the kids.** Caring for our children during treatment days, doing the school run, or entertaining them on bad days would be amazing.
- **Stash some vomit bags.** Get some vomit bags from the clinic or a chemist, and stash them in your bag or car, just in case. We might never need them, but a bag is much more dignified than using a roadside gutter.
- **Meal delivery.** Make or buy some frozen or freezer-ready meals and deliver them to the door (but don't expect to stay for a visit).
- **Walk the dog or feed the chooks.** If it's regularly or occasionally, just let us know - we may want to tag along.
- **Regular maintenance.** Lawn mowing, garden maintenance, cleaning gutters, cleaning the bathroom or kitchen, washing and folding, vacuuming etc.
- **Rostering volunteers.** Organise a group of friends to help at the times and in the ways that is needed (and of course there are apps to help with this). Just make sure you involve us in your plans too.
- **Donate blood and marrow.** Even if we never need it ourselves, you could save someone's life by regularly donating blood and going onto the bone marrow registry.

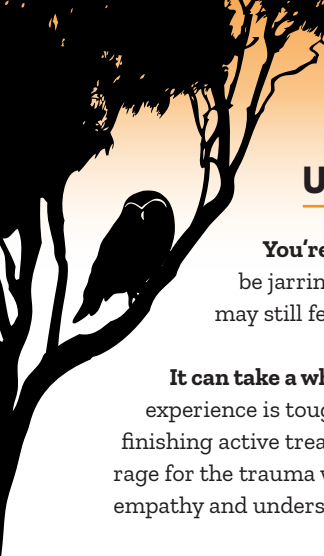


Gift ideas



- **Feed us.** Food is always welcome, including fresh or freezable main meals, snacks, chocolate, and cake. While ginger may help with nausea and sour lollies cover foul-tasting medicine, mix up the flavours. Some soft cheeses, sushi, seafood, processed meats and alcohol might be off limits during treatment - best to check first.
- **Brain activities.** We love entertainment and items that can be easily picked up when we have the energy or brain capacity and waiting for appointments - puzzles, jigsaws, streaming services, card games, and light-hearted novels.
- **Indulge our hobbies.** Feed our soul and buy the things that will help us keep doing the things we love - you know what they are.
- **Gift cards are fab.** Allow us to pick exactly what we want, when we want it - Netflix, Amazon, Audible, Apple App Store, Google Play, grocery stores, online clothes shopping, prepaid Mastercard or Visa for parking costs.
- **Pamper packs.** Choose sensitive moisturisers and soaps, soothing teas and the usual special treats. Best to have a long expiry for massage and spa vouchers so we can go when we're well enough. For inspiration or an easy option, there are cancer care packs available for sale online.
- **Clothing.** Soft, elasticised and comfortable are the rules for what to wear during treatment and recovery. Soft non-slip socks are also useful for home or hospital use, and sassy designs can make us smile.
- **Beanies and headwear.** Our choice of headwear could change, so a gift voucher may be a better option.
- **Donate money.** You may like to donate money to cancer research or a fabulous not for profit, on our behalf.
- **Avoid smelly things.** Tolerance for scented items may be reduced during treatment - avoid buying heavily scented gifts, or don't be offended if we can't handle the scent right now.
- **Bulk-buying treats.** Eating too much of one thing during treatment may create an unpleasant association with being sick. Stick with the small packs of our favourite treats for now.
- **Loud and proud.** Not everyone wants the attention associated with wearing clothing emblazoned with 'fuck cancer' slogans or awareness ribbons - check beforehand.
- **Avoid flowers.** House plants and fresh flowers are usually banned on oncology wards - one reason is because fungal spores can potentially harm someone who is immunosuppressed. Plus, when you're unwell it can be depressing to watch flowers wilt and die.





Understand the long haul

You're all done. After the whirlwind of diagnosis and treatment, it can be jarring to be sent off into the world without medical supervision. We may still feel sick, exhausted, and shell-shocked and not up to celebrating.

It can take a while. Recovering both physically and emotionally from a cancer experience is tough and can realistically continue for months or years after finishing active treatment, even with counselling. We have every right to grieve and rage for the trauma we've endured, so no, we won't 'just get over it'. Expect that your empathy and understanding might be needed well beyond the end of active treatment.

Relapses and recurrences. Cancer can return and it's something we may fear for years to come. Despite our best efforts, we know we can't stop cancer invading our body again, and it's just another trauma to add to the list.

Not all cancers can be cured. Whether it's a late diagnosis or lack of suitable effective treatment, some cancers cannot be 'cured'. Despite amazing medical advancements, younger adults still die of cancer. Some people can live for years with ongoing treatment keeping their cancer stable, while for others that is not possible. Yep, it's really shit.

Cancer-induced PTSD is real. Challenging memories and emotions may be triggered by really random things as well as the more obvious ones too. So don't be surprised if we avoid the known triggers and react strongly to the unexpected ones - it's something we will have to work through.

The gift that keeps on giving. While some side effects may fade and hair may grow back, some side effects of cancer and treatment may not appear until years later and require additional treatment and challenges. We are not hypochondriacs, it's just our new reality.

Introducing scanxiety. Checkup scans are a regular reminder of what has happened and the possibility that the cancer may return. No matter how long has passed since treatment, it can be anxiety-inducing going for a scan and then waiting for the results. If you know a scan is coming up we would appreciate you checking in, and distracting us if that's what we need.

Anniversaries. Some people mark the date of their diagnosis, when they ended treatment, got their first clear scan, or another treatment milestone. Regardless, remember that it can be a time of high emotions. If you know it's coming up, be extra patient, check in and bring cake.

Finally,

All you can do. We know it's a lot to think about and take in - oh trust us, we know! Just remember - treat us the same, bring us treats, love us and be our friend. That's all we ask and it's truly the best thing you can do.

Look after yourself. If you're having trouble with our diagnosis, seek the assistance of a trained mental health professional and take care of yourself. You can't help us if you're struggling, and we don't want that for you. There are services available for caregivers, so make the most of them.

We love you and we appreciate you.

♡ Thank you for all that you do.





www.ninoxcsc.com.au

