

Support and resources to help you on your bladder cancer journey

What support services are available to you?

There are various support services for patients and carers affected by bladder cancer. Depending on your situation, some services may benefit you more than others. It is important to remember that not all such services are necessary, and it is important to prioritise what will provide you the most benefit to you, both physically and emotionally.

We can't stress enough how vital it is for you to reach out to your family and friends first. This family and friend support network will provide you with the most valuable emotional and practical support, as well as help you to access any support services you may require. For more information on this, see *'How can your family and friends help you?'* on the next page.

While your GP and team of medical professionals can provide you with all the necessary medical support, it's very likely you'll need further support and expertise (offered by individuals and organisations) to help you through your bladder cancer journey.

These useful summary sheets will help you answer the following questions you may have:

- **How can your family and friends help you?**
- **Are you seeking support to manage pain?**
- **Are you seeking assistance with your stoma?**
- **Are you looking for someone to talk to?**
- **Do you live in a rural area, and need practical support?**
- **Are you in need of financial support?**
- **Are you looking for advice on diet and exercise?**



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How can your family and friends help you?

While your circumstances in your stage of treatment, home life, family situation, friend network and emotional state will differ from other patients, those closest to you will always be willing to help along each stage of your journey.

Your bladder cancer journey will allow you to reflect and reconnect with your immediate family, extended family, and friends, and form a support network, which will fight this together. By spending time together, talking about your feelings, and gaining practical support, you will become closer with your family and friends, resulting in a more positive experience for everyone.

On the news of your diagnosis, you may hear: “Let me know if there is anything I can do to help.”

Don't be shy. Take them up on their offer. An enormous amount of time and energy is needed to manage your way through your bladder cancer journey. The more help you can get, the better.

Let people know when they can take you to an appointment, provide a meal, or babysit. They will always be willing to help, it will make them feel wanted and it will strengthen your support network.

We cannot recommend strongly enough the need to identify one or two people who you are very close to (a family member or good friend) to be responsible for coordinating all aspects your care. You will likely become overwhelmed by everything that needs to be done and it's one less stress for you to know that someone has the big picture taken care of, so you can focus on being well.

Below are some examples of the practical support that your family and friends can provide, to give you more time and relieve any stress:

- Childcare/school drop-offs and pick-ups
- Preparing and delivering meals
- Co-ordinating a hospital visit schedule
- Providing transport to appointments, check-ups, etc.
- Household chores
- Managing your medication regimen
- Organising your return to work



The Cancer Council provides information and support for carers, and gives further examples of how carers and patients can work together through your journey. Click [here](#) to access more on this.



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Are you seeking support to manage pain? (1/3)

It is normal to experience different types of pain, and there are various services to help you manage and alleviate pain. The type and extent of the pain you may experience will depend on the type of surgery or treatment you have, and the side effects you're having, and will be different for everyone.

Your primary contact for pain and symptom management should be your medical oncologist. This is a large part of their role in addition to the advice they provide for cancer treatment.

GPs can also provide good advice, and if required can provide a GP referral to specialist pain clinics which can be found at major hospitals. Here they will educate patients about pain – especially chronic pain – and provide a multidisciplinary approach including medical pain specialists and nurses, relaxation, music and mindfulness.

Below, we've outlined some other practitioners that may be of help to your pain needs...

Palliative Care

It is important to note that Palliative Care does not just entail 'end of life' care. It is a means by which your symptoms can be managed in your home, a hospital or an aged-care facility, to improve quality of life and take some burden off your primary carers and family.

Patients are typically referred to a pain management medical specialist by their oncologist; however, alternatives can be accessed by contacting Palliative Care Australia.

<https://palliativecare.org.au>

Physiotherapy

Physiotherapists will help you with pain management, strengthening and flexibility, and incontinence control. Often, your oncologist will refer you to a physiotherapist if it is required; however, if you feel that you need further assistance, you can find more information and seek out an accredited physiotherapist through the Australian Physiotherapy Association.

<https://choose.physio>



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Are you seeking support to manage pain? (2/3)

Natural Therapies

Natural Therapies are an increasingly popular way for patients seeking assistance with pain management to improve their general bladder health and well-being, and relieve stress. They can involve acupuncture, remedial massage, aromatherapy, and herbal medicines. Please note, however, that there is no evidence that natural therapies provide a cure to cancer.

Natural Therapists can be sought out through the Australian Natural Therapists Association. They provide information on many specific therapies and can direct patients to various practitioners.

<https://www.australiannaturaltherapistsassociation.com.au>

Medicinal Cannabis

While a controversial and confusing topic, a further method of pain and symptom management is the use of medicinal cannabis. This can come in varying forms but the most common is cannabis oil.

Cannabis oil has two main active ingredients (cannabinoids) – CBD, the major component, which is anti-psychoactive; and THC, which has psychoactive properties (giving that 'high' feeling).

Medicinal cannabis is illegal for patients to access directly in Australia. Australia's Therapeutic Goods Administration (TGA) regulates the supply of medicinal cannabis. Doctors can apply to the TGA to supply medicinal cannabis to certain patients through the Authorised Prescriber Scheme and the Special Access Scheme. Patients may be able to access medicinal cannabis through a specialist doctor, their GP, or if they are taking part in a clinical trial:

<https://www.tga.gov.au/accessing-unapproved-products>



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Are you seeking support to manage pain? (3/3)

It can, however, be a lengthy and very challenging process to get approval. This has led to an increasing trade in illegally supplied medicinal cannabis.

It is also useful to know the difference between cannabis (CBD) oil and hemp oil. CBD oil has a significant content of cannabidiol. It is made from the flowers, leaves and stalks of hemp and not from its seeds like hemp oil. Hemp oil has no medicinal value.

Online Support Groups

Connecting with other patients and carers provides great information on how other people have managed their pain, and can help you make decisions on how to proceed if you experience pain.

These peer support groups are always incredibly supportive, provide real-time information, and help you to realise that you are not alone. Through them, you will see that others are going through a similar journey to you. There are no embarrassing or dumb questions as you are all in it together, and everyone wants to help.

We recommend that you use this information in combination with the recommendations that you receive from your medical and allied health professionals.

Facebook Group

Bladder Cancer Support – Australia / New Zealand

<https://www.facebook.com/groups/bladdercancersupportaustralia/>

The Cancer Council

The Cancer Council also provides answers to many questions and information to help manage pain.

<https://www.cancercouncil.com.au/cancer-information/managing-cancer-side-effects/overcoming-cancer-pain/>



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Are you seeking assistance with your stoma?

Before your surgery, your doctors and stoma nurse will provide you with all the tools and information you will need to manage your stoma. If you feel you need additional support, there are services to help you.

If you experience an emergency with your stoma, contact your stoma nurse or go through your local emergency department for attention.

The Australian Council of Stoma Associations provides information on living with, and managing, your stoma, as well as supplies and practical support.

Their website provides information and advice on diet, body image, travel, financial support and products. You can find all your necessary supplies, resources and even a public restroom map. It also provides links to various support websites and support groups on a state-by-state basis.

<https://australianstoma.com.au>

In addition to face-to-face support groups found through the Australian Council of Stoma Associations, online support groups are an incredibly valuable source of information, and peer support from other patients. These peer support groups are always incredibly supportive, provide real-life information, and make you realise that you are not alone. They are going through a similar journey to you, and therefore there are no embarrassing or dumb questions as you are all in it together, and everyone wants to help.

Facebook Group

Bladder Cancer Support – Australia / New Zealand

<https://www.facebook.com/groups/bladdercancersupportaustralia/>

The Cancer Council

The Cancer Council also provides plenty of information on living with a stoma, and an information hotline you can call.

<https://www.cancercouncil.com.au/bladder-cancer/after-cancer-treatment/bladder-reconstruction/>



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Are you looking for someone to talk to? (1/2)

The first and best people to talk to throughout your journey are your friends and family. The services outlined here are if you feel you haven't got a strong enough support network, or if you are seeking more independent or professional advice.

Your team of medical professionals may offer you a counselling service through your hospital, and if you believe this may help, then it is important that you take the opportunity.

Psychologists

Psychologists can help you manage your emotions by providing coping strategies for you and your support network of family and friends, to improve your emotional health on your journey. Your GP can recommend a psychologist for you, or you can seek out an accredited psychologist through the Australian Psychological Society. Their website also provides information on what psychologists can do to help you and common topics in psychology.

<https://psychology.org.au>

Your GP can assess you, and provide up to 10 appointments with psychologists, subsidised through Medicare, as part of a Mental Health Care Plan for you. For more information, you can ask your GP, or visit the following website.

<http://www.health.gov.au/internet/main/publishing.nsf/content/mental-ba-fact-pat>

Counselling and Social Work

Discussing your social, professional and practical life with counsellors or other patients can lead to effective solutions to help you. By managing how your life is affected by bladder cancer, social workers and counsellors can help you return to normality, and support your carers and family in this difficult time.

Online support groups are an incredibly valuable source of information and peer support from other patients. These peer support groups are always incredibly supportive, provide real-life information, and make you realise that you are not alone. You will connect with others who are going through a similar journey to you. There are no embarrassing or dumb questions as you are all in it together and everyone wants to help.



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Are you looking for someone to talk to? (2/2)

Facebook Group

Bladder Cancer Support – Australia / New Zealand

<https://www.facebook.com/groups/bladdercancersupportaustralia/>

The Cancer Council

The Cancer Council provides many of the services that can help you and your family, including phone and face-to-face support groups, financial and practical support, home help, and a library of information.

<https://www.cancercouncil.com.au/get-support/coping-with-cancer/>



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Do you live in a rural area and need practical support?

Living in a rural area may require some patients to travel to receive treatment, have check-ups and take tests.

Fortunately, the Australian Government is developing several channels of support for cancer patients in regional and remote areas.

Regional Cancer Centres

Regional Cancer Centres are being continually developed and refurbished to allow easier access and less travel for regional and remote patients, through multidisciplinary, patient-centred care. For more information and a list of Regional Cancer Centres, please read the following article.

<http://www.health.gov.au/internet/publications/publishing.nsf/Content/cancer-policy-booklet~What+the+Government+is+doing+to+tackle+cancer>

Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)

If travel is necessary, the Government has also introduced the IPTAAS. For those without other means of financial assistance, the IPTAAS provides subsidised travel and accommodation for patients who need to travel to receive treatment.

IPTAAS subsidies include travel for private vehicles, public transport, private stays, and various rates for other accommodation, all outlined on their website.

<http://www.enable.health.nsw.gov.au/services/ipaas>

Angel Flights

Angel Flights provide non-emergency rural flights to access medical treatment. It must be noted that they are not a medical provider and can act only as a means of transport from rural areas.

<https://www.angelflight.org.au>

The Cancer Council

The Cancer Council also provides information and services to support you with any transport, accommodation, or home help.

<https://www.cancercouncil.com.au/get-support/transport-accommodation-and-home-help/>



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Are you in need of financial support?

Bladder cancer treatments can be expensive, and result in a drop in working hours and loss of income. The Cancer Council provides comprehensive legal and financial services and advice.

Government Support

The ATO allows patients in certain circumstances early access to their superannuation. To find out if this is appropriate for you, visit the ATO website.

<https://www.ato.gov.au/individuals/super/withdrawing-and-using-your-super/early-access-to-your-super/>

Legal Services and Advice

The Cancer Council can connect you with volunteer legal specialists, who can assist you with wills & powers of attorney, superannuation access, insurance, and other legal matters.

<https://www.cancercouncil.com.au/get-support/legal-and-financial-assistance/free-legal-services/>

Financial Planning and Counselling

The Cancer Council can connect you with volunteer financial planners and counsellors, who can assist you with managing your income and expenses, managing medical bills and other financial concerns you may have.

<https://www.cancercouncil.com.au/get-support/legal-and-financial-assistance/financial-planning-counselling/>

Workplace Advisory

The Cancer Council can connect you with human resources advisors, who can give you guidance on workplace matters, such as medical leave, return to work, and disclosing your diagnosis to employers and colleagues.

<https://www.cancercouncil.com.au/get-support/legal-and-financial-assistance/workplace-advice/>

Continence Aids Payment Scheme

For bladder cancer patients that require products and services to manage incontinence, the Department of Human Services has options to help you afford them.

<https://www.humanservices.gov.au/individuals/services/medicare/continence-aids-payment-scheme>



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Are you looking for advice on diet and exercise?

Diet and Exercise play key roles in your recovery from bladder cancer treatments. Typically, a physiotherapist and dietitian are provided to you in your hospital by your medical team to give you advice in different stages of your recovery.

If you are out of hospital, there are other means by which you can seek preventative and proactive support.

For any services of this type, your first point of contact should be your GP. Typically at less expense to you, you can see your GP and nurse to build a General Practice Management Plan, and arrange cross-referrals to nutritionists, exercise physiologists, and other specialists to provide a more well-rounded, personal approach to your recovery. For more information on such plans, please visit this site.

Chronic Disease Management - Patient Information - <https://bit.ly/2Gq0TzF>

Nutrition

For specific advice during your bladder cancer journey, nutritionists can provide a holistic view on your overall health, as well as during your treatment and recovery. Nutritionists will assess your lifestyle and diet to give you personalised advice.

You can find a Nutritionist through the Nutrition Society of Australia.

<http://nsa.asn.au/find-a-registered-nutritionist/>

The Cancer Council

The Cancer Council provides general information about nutrition and cancer in the following online booklet.

<https://www.cancercouncil.com.au/wp-content/uploads/2016/07/UC-Pub-CAN756-Nutrition-Web-Lo-Res.pdf>

Similarly, the Cancer Council provides general information and advice about exercise and cancer.

<https://www.cancercouncil.com.au/get-support/exercise-and-cancer/>



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