

I'm a carer/family member/supporter



Dealing with a family member or friend's cancer diagnosis isn't easy. It may take a long time to adjust to. It can be physically, mentally and financially draining. If you're finding this experience challenging, you're not alone. In fact, research has shown that carers often experience higher levels of distress than people with cancer themselves. Here is some information that other rural people affected by cancer think might help.

1. What to expect

- A range of feelings such as **fear, anger, frustration, resentment, helplessness, loneliness, guilt, sadness, loss and/or grief**. Try not to be critical of yourself for feeling this way – most people in your situation feel like this too.
- The way you feel may change rapidly. This is also okay.
- Significant **changes to your routine** – particularly if the patient needs to travel to access treatment.
- Simple, practical tasks such as picking up children from school can suddenly become very challenging. **Don't be afraid to ask for or accept help.**
- Feeling as though you want to 'fix' the problem. It can be **difficult to accept that this is outside your control**. Feeling as though you should be able to solve the problem can be an additional burden.
- The cancer journey is a like a **rollercoaster ride**. One day the person with cancer may feel good, the next day they may not. You may feel as though you're one step behind them. This can be challenging and frustrating for everyone.
- As a carer/family member/supporter, you may feel **left out of conversations** with medical professionals. If the person with cancer is happy to allow it, don't be afraid to ask health professionals questions on their behalf.
- It can be upsetting if the person with cancer chooses to attend appointments on their own (without assistance). However, it's important to recognise that they have the right to do so.
- Be aware that the person with cancer may experience changes in their behavior and attitude, just as you do. For example, they may become more assertive. This can be difficult to adjust to and may affect relationships.
- When the patient's treatment is finished, **reminders of cancer may be distressing** for them. You may need to be careful to treat this with sensitivity.
- Be aware that **seeking out additional sources of support may be particularly important when treatment is complete** and the person with cancer has reduced contact with their treating team.
- For further information on **what to expect with various types of tests/imaging**, visit http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/ct_medicalprocedures?open&cat=Medical_procedures_-_Diagnostic_imaging.
- Let John show you **how to catch a Cancer Council SA bus** from either Cancer Council Lodge (Greenhill) or Cancer Council Lodge (Flinders) and what to expect along the way by **watching the videos** on the Country Cancer Support website.

2. Sharing the diagnosis with family and friends

Sharing a diagnosis of cancer isn't easy. You may feel uncomfortable talking about it and be unsure about how others will respond. It may also be tempting to keep information to yourself to avoid worrying your loved ones. However, living in a rural community means it's likely that people will probably find out about the diagnosis quite quickly, so being honest with those who are close to you is important. You needn't tell everyone everything, but it might be helpful to encourage sharing the news to ensure you don't face cancer alone.

Tips to help tell others:

- Sit down with the person who has received the cancer diagnosis and **make a list of who to tell and when to tell them together**. This will help prevent people being upset and conflict arising. You may find it helpful to tell those closest to you first and enlist their help to tell others.
- **Be prepared for questions.**
- Keep in mind that family and friends will probably also find the diagnosis difficult to adjust to and **probably won't know what to say**. They may even distance themselves from the patient or yourself, or react in other ways you find hurtful (e.g. claiming they know "exactly how you feel" even though they've never had cancer). Usually this isn't a deliberate attempt to upset you. Instead it happens because they feel awkward or uncomfortable.
- A good way to help friends and extended family to adjust is to **suggest how you would like them to behave**. You might tell them that they don't need to say anything – you just appreciate being with them. Most people like to help in a practical way, so giving them a job will also help them to adjust (and you to cope!).
- If you're telling children, reassure them that cancer isn't contagious and that no one is responsible for it. Also give them opportunities to share their feelings and fears but where possible, **keep as much 'normal' structure** in their lives.
- Although many people fear they might upset those who are close to them if they are open with them, doing so might in fact provide you all with some relief. People around you are probably picking up clues on how you are feeling, even if you haven't told them directly. **You might find (as others have) that hiding emotions is actually more stressful and draining for all involved than simply expressing them.**

3. Affordable accommodation options

If you are considered an 'approved escort' by PATS, your travel and accommodation costs may be covered by this scheme in the same way that the patient's costs are covered (but possibly only for a limited period of time). For more information visit the 'Financial assistance to get to Adelaide' page of the Country Cancer Support website or the PATS website at www.countryhealthsa.sa.gov.au/pats.

A range of accommodation facilities are available. Most people find that the subsidised facilities specifically provided for cancer patients are very good. However, commercial options are also listed below. PATS covers almost all of the costs associated with staying in the subsidised accommodation options. With the commercial options, you may be left with a gap. Remember that bookings are essential and you should book as early as possible to avoid disappointment. If you have difficulty with stairs, mention this when booking so that you don't end up with a room that you can't get to!

Subsidised accommodation

- **Cancer Council Lodge (Greenhill)** - previously known as Greenhill Lodge (204 Greenhill Road, Eastwood, phone (08) 8291 4200 or email greenhilllodge@cancersa.org.au). This air-conditioned motel-style accommodation facility is owned and run by Cancer Council SA. Rooms sleep between 2 and 5 people and include all linen, tea and coffee making facilities, a fridge, free Foxtel, free access to wifi and a telephone (local and STD calls at a cost).

Reasonably priced evening meals can be purchased in the dining room or guests can have access to communal kitchen facilities. There is off-street parking, a recreation room, BBQ, free laundry facilities and a Cancer Council SA bus service that takes patients to and from the RAH, St Andrews, or the Flinders Medical Centre several times a day for medical appointments. Morning teas are held every Thursday morning to give guests a chance to get to know each other. Shopping trips and weekend outings (driven by volunteers) are also available to guests. A social worker is available onsite several days a week to assist with any difficulties (e.g. financial or emotional issues).

Cost: For cancer patients and their carers, the cost is \$30 per night for a single room and \$60 per night for a double room. If you have a health care or pension card and are eligible for PATS, this cost will be covered completely by PATS. If you don't have a health care or pension card, but are eligible for PATS, you will be charged the first night's accommodation (the PATS co-contribution). Cancer Council SA can 'bulk-bill' PATS directly on behalf of eligible guests, to reduce out-of-pocket expenses. Additional occupants are welcome to stay in your room for a small fee, if bed configuration allows.

- **Cancer Council Lodge (Flinders)** - previously known as Flinders Lodge (27 Dequetteville Terrace, Adelaide, phone (08) 8332 8222 or email flindersmotel@cancersa.org.au). This air-conditioned motel-style accommodation facility is owned and run by Cancer Council SA. Rooms sleep between 2 and 5 people and include all linen, tea and coffee making facilities, a fridge, free Foxtel, free access to wifi and a telephone (local and STD calls at a cost). Reasonably priced evening meals can be purchased in the dining room or guests can have access to communal kitchen facilities. There is also one off-street car park per room, a recreation room, BBQ, free laundry facilities and a Cancer Council bus service that takes patients to and from the RAH, St Andrews or the Flinders Medical Centre several times per day for medical appointments are also available. Morning teas are held every Wednesday morning to give guests a chance to get to know each other. Shopping trips and weekend outings (driven by volunteers) are also available to guests. A social worker is available onsite several days a week to assist with any difficulties (e.g. financial or emotional issues).
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Let John show you what you can expect when staying at Cancer Council Lodge- Greenhill and/or Cancer Council Lodge- Flinders by **watching the videos** on the Country Cancer Support website.

- **Cancer Council Lodge (Seaview)** - previously known as Seaview Lodge (3 Seaview Street, Fullarton, phone (08) 8291 4200 or email greenhilllodge@cancersa.org.au). This is a group of self-contained one bedroom units (and one upstairs two-bedroom unit) owned and run by Cancer Council SA. All linen is provided. Each air-conditioned unit has its own off-street parking, kitchen and laundry facilities. Within walking distance is a supermarket and service station. While telephones are available, phone cards are required to make calls. Guests at this facility are welcome to drive to the other Cancer Council Lodges (Greenhill or Flinders) and access any of the additional services provided at those larger facilities (e.g. weekly morning teas, onsite social workers, bus services to hospitals as outlined above).
Cost: For cancer patients and their carers, the cost is \$30 per night for a single room and \$60 per night for a double room. If you have a health care or pension card and are eligible for PATS, this cost will be covered completely by PATS. If you don't have a health care or pension card but are eligible for PATS, you will be charged the first night's accommodation (the PATS co-contribution). Cancer Council SA can 'bulk-bill' PATS directly on behalf of eligible guests, to reduce out-of-pocket expenses. Additional occupants are welcome to stay in your room for a small fee, if bed configuration allows.
- **City View Apartment** (Unit 26/177 Angas St, Adelaide, phone (08) 8235 7000). This self-contained three-bedroom, two-bathroom unit with off-street parking for one car is available for short or long term stays. It is run by the Cancer and Bowel Research Trust in affiliation with

Breast Cancer Australia and Kids Cancer Research Trust. Linen is provided. People with any type of cancer are welcome.

Cost: If eligible for PATS, this will cover the cost (minus the \$30 co-contribution if applicable). PATS can be invoiced directly so you don't have any out of pocket expenses. If you aren't eligible for PATS, the cost is \$60 per night.

- **Leukaemia Foundation Apartments (Wayville)** (34 King William Road, Wayville, phone (08) 8100 9455 or 1800 620 420). These self-contained apartments (2 upstairs and 2 downstairs) sleep up to 4 people and are available to patients and their carer who are having treatment for a blood cancer like leukaemia, lymphoma or myeloma. Linen and off-street parking are provided. Each apartment contains a kitchen, laundry and bathroom and there is a shared outdoor entertaining/BBQ area. Patients must be accompanied by a carer when staying at these facilities.

Cost: This service is provided at no cost to the patient and carer.

- **Leukaemia Foundation Apartments (Richmond)** (287 Richmond Road, West Richmond, phone (08) 8100 9455 or 1800 620 420). These self-contained apartments with off-street parking sleep up to 4 people and are available to patients and their carer who are having treatment for a blood cancer like leukaemia, lymphoma or myeloma. Linen is provided. Each apartment contains a kitchen, laundry and bathroom and there is a shared outdoor entertaining/BBQ area/play equipment for children. Patients must be accompanied by a carer when staying at these facilities.

Cost: This service is provided at no cost to the patient and carer.

- **Ronald McDonald House** (271 Melbourne Street, North Adelaide, phone (08) 8267 6922, www.rmhc.org.au). These facilities are available to the families of seriously ill children who are having treatment at the Women's and Children's Hospital. They can accommodate up to 20 families (10 in communal living and 10 in independent living units for stays of more than 3 months). Each family has a private bedroom and bathroom. All share a dining room, two well-equipped kitchens, a playroom and a parents' retreat. The first time a family visits, a social worker at the Women's and Children's Hospital must make a referral to this facility (phone (08) 8161 7381). After that, families may self-refer.

Cost: If eligible for PATS, this will cover the cost (minus the \$30 co-contribution if applicable). PATS can be invoiced directly so you don't have any out of pocket expenses.

- **RAH Residential Wing** (Northern end of hospital grounds, phone (08) 8222 5169). This basic facility is located at the back of the hospital (northern end) and contains single rooms with a communal kitchen, lounge, laundry, uni-sex bathroom and computer facilities. Linen is provided. Parking is not available. Guests are required to clean their own rooms. There is no air-conditioning and kitchen utensils and facilities are scarce. Bring your own if you plan to stay for a long time and want to cook. Rooms are limited to people who are receiving treatment or who have family receiving treatment at the RAH, Women's and Children's or Repatriation Hospitals. Only two relatives per patient can be accommodated at these facilities at one time.

Cost: \$18.46 plus GST per night for a single room.

- **Heart Beat House** (21 Beckman St, Glandore, phone (08) 8177 2270). This facility offers shared accommodation with individual rooms. Bathroom, kitchen, dining room and lounge facilities are shared. Linen is provided. Priority is given to cardiac patients, but if places are available, cancer patients can be accommodated too.

Cost: \$20 per person per night. If you are eligible, PATS can be invoiced directly so you don't have any out of pocket expenses.

- **Rosemary's Place** (7 Rose Terrace, Wayville, phone 0416 722 870, visit www.rosemarysplace.org.au or email info@rosemarysplace.org.au). This charity (run by volunteers and specifically founded to support country people) has two homely self-contained, air-conditioned maisonettes that sleep up to four people each.

Cost: One is available for short term stays (at a base cost of \$85 per night) and the other is available for long term stays (at a base cost of \$60 per night). Long-term guests can ask for PATS to be invoiced directly.

- **Country Women's Association** (30 Dequetteville Terrace, Kent Town, phone (08) 8332 4166). The CWA provides accommodation to members and non-members in both units and individual rooms. The individual rooms share bathroom, lounge, kitchen and laundry facilities.

Cost: Units range from \$80-\$200. The shared facility rooms cost \$65 for a single room, \$110 for two people and \$110 for a family room (with the option to add a third and fourth person for \$25 per additional person).

Commercial hotels/motels

If you find that all of these options outlined above are booked, you may need to consider the following commercial facilities. Please note that these hotels/motels are not setup specifically for cancer patients. Therefore, if you need to stay for a long time, explain your situation and ask whether they are able to offer any long-term or patient discounts.

Near the city

- **The Sands Motel** (198 Glen Osmond Road, Fullarton, phone (08) 8379 0066, visit www.thesandsmotel.com.au or email bookings@thesandsmotel.com.au).
- **Fullarton Motor Lodge** (284 Glen Osmond Road, Fullarton, phone (08) 8379 9797). If you stay 3 nights or more, discounts apply.
- **Princes Lodge Motel** (73 Lefevre Terrace, North Adelaide, phone (08) 8267 5566 or visit www.princeslodge.com.au).
- **Harriett's Cottage** (phone (08) 8271 6724 or 0408 083 584, visit www.harriettscottage.com.au or email info@harriettscottage.com.au). Self-contained cottages/houses/units located in the city, at Parkside and at Largs North. Parking, long-term discount and small discount for cancer patients available).
- **Adelaide Caravan Park** (46 Richmond Street, Hackney, phone (08) 8363 1566, visit www.adelaidecaravanpark.com.au or email adelaide@adelaidecaravanpark.com.au). Discount available for stays of 7 nights or more.

Near the Queen Elizabeth Hospital

- **Lindy Lodge Motel** (445 Torrens Rd, Woodville Park, phone (08) 8268 2333, visit www.lindylodgemotel.com.au or email res@lindylodgemotel.com.au).
- **Woodville Serviced Apartments** (11-19 Woodville Rd, Woodville South, phone (08) 8347 1966). Bookings taken by Sutherland Court Retirement Village. Open plan studio apartments that sleep two people. Long-term rates negotiable.

Near Flinders Medical Centre

- **Nunyara Holiday Unit** (5 Burnell Drive, Belair, phone (08) 8278 1673 or email nunya@unitingvenueusa.org.au). Self-contained family units.
- **Marion Hotel** (849 Marion Road, Mitchell Park, phone (08) 8276 8888). Upstairs self-contained rooms that sleep up to 2 people. Off-street parking and discounts for cancer patients available.
- **Morphett Arms Hotel** (138 Morphett Road, Glengowrie, phone (08) 8295 8371). Upstairs self-contained rooms that sleep up to 4 people. Parking and weekly rates available.
- **Tonsley Hotel/Motel** (1274 South Road, Clovelly Park, phone (08) 8276 8099). Motel-style single and double rooms. Parking and discounts available for patients.
- **Comfort Inn On Marion (Supercentre)** (540 Marion Road, Plympton Park, phone (08) 8371 2899). Single and double rooms that sleep up to 6 people. Parking and long-term/cancer patient discounts available.
- **Warradale Hotel** (234 Diagonal Road, Warradale, phone (08) 8296 1019). Rooms sleep between 2-6 people. Weekly rates available.
- **Marion Holiday Park** (323 Sturt Road, Bedford Park, phone (08) 8276 6695). Various types of cabins with linen provided. Parking on site. 15% discount for patients of the Flinders Medical Centre.
- **Sturt River Caravan Park** (Brookside Road, Darlington, phone (08) 8296 1113). Large and small cabins, parking, linen and cooking facilities provided.

Near the Lyell McEwin Hospital

- **Elizabeth Motor Inn** (582 Main North Road, Elizabeth, phone 1800 066 288, elizabethmotorinn@fenet.com.au). 10% discount for people attending the Lyell McEwin Hospital.
- **Mawson Lakes Hotel and Function Centre** (10 Main Street, Mawson Lakes, phone (08) 8360 3500, www.mawsonlakeshotel.com.au). Long term discounts available.
- **Gawler Caravan Park** (Main North Road, Gawler, phone (08) 8522 3805, www.gawlercaravanpark.com.au). Cabins with ensuites sleep up to 6 people. Linen provided. A cabin with wheelchair access available. 10% discounts for long-term bookings.
- **Highway 1 Caravan and Tourist Park** (Port Wakefield Road, Bolivar, phone (08) 8250 3747). Two- or three-bedroom, self-contained units. Parking available.
- **Old Spot Hotel** (1995 Main North Road, Salisbury Heights, phone (08) 8258 2096). Upstairs accommodation sleeping up to 4 people. Parking available. Long-term discounts.
- **Smithfield Hotel Motel** (1 Main North Road, Smithfield, phone (08) 8254 6011). Self-contained rooms that sleep up to 4 people. Parking and weekly rates available.
- **Rose and Crown Hotel** (100 Phillip Highway, Elizabeth South, phone (08) 8255 2233, www.theroseandcrown.com.au). Rooms sleep up to 5 people. Weekly discounts available.

4. How you can help your friend/family

- If you haven't spoken to your family member/ friend since their diagnosis, **directly approach the issue** by saying something like, *"I'm sorry to hear you've been diagnosed with cancer. How are you going?"* Most people appreciate an honest acknowledgment of their situation, rather than 'beating around the bush'.
- Be aware that **your relationship with the person with cancer may come under great stress** during diagnosis and treatment (particularly if you're their carer or close family member).
- If you're a friend, speak to the patient and their family about the role they would like you to play
- **Continue with your usual communication.** Many people worry that they won't say the right thing to the patient, that they might upset them or that they should "be strong" or hide negative emotions for their sake. Being honest about how you feel, asking the patient how they feel and being a good listener are in fact some of the most helpful things you can do. Simply talking about distress provides relief, so try not to change the subject, even if you feel a bit uncomfortable.
- Be honest – **don't give unrealistic assurances or promise to do things that you can not realistically do.**
- Where possible, let the person with cancer **continue with their usual routine, activities and previous roles** as much as possible. They may be sensitive to others taking on tasks and responsibilities.
- Continue to include the person with cancer in planning various aspects of family life and social activities by asking them for their advice- they will probably still want to contribute.
- Structure time out with the person with cancer when you 'don't do sickness'. It is important to **spend time together that is not illness-related** (e.g. watching a movie).
- Be open to a **sense of humour.**
- Remember the person with cancer will probably be worried about how their diagnosis is affecting you too. If you're seeing a professional such as a counsellor, state this honestly. This may come as a relief to the person with cancer and make it easier for them to do the same.
- **Offer to go along to appointments** (check-ups, tests and treatment).
- Prepare food and drink to encourage eating, but be aware that **treatment often changes taste and appetite.**
- **Make a list** of all of health professional's names and contact details. Place it in a prominent position for easy access (e.g. near the phone), so that anyone can access it if you're not there.

- As a friend, **help create opportunities for the carer to have a break**, for example by offering to sit with the person with cancer for a few hours to enable the carer to go out and do something for themselves.
- Try not to be too offended if the person with cancer does not seem to appreciate all that you're doing. **It's common for carers to feel like a 'punching bag'**.
- Try to **encourage a return to a normal routine** as soon as possible.
- When treatment is complete, it may be helpful to have **advice on how to carry out the caring tasks from a community nurse** on a home visit. An Occupational Therapist may also be able to help you make changes to home, or provide special equipment to make things easier (e.g. handrails). Your GP or community health team will be able to advise and provide more information about accessibility.
- **Offer to help with tasks** such as cooking, cleaning, laundry, ironing, shopping or gardening, driving to appointments, picking up children from school, looking up information, filling out forms, sorting out legal or financial issues, keeping others updated, accompanying them on a walk. If the person needs to travel for treatment, making them meals that can be frozen and taken with them may be particularly useful. When offering to help, be clear about exactly what you can do and when.
- Be careful about offering advice and telling stories about other people who have experienced cancer. They are not always helpful or appreciated.

5. How you can look after yourself

- Remember that **it is okay to feel upset, angry, to cry and to tell people how you feel**. You don't need to remain positive all of the time. Feeling as though you must be cheerful all of the time is an extra and unnecessary burden.
- Be aware of the stress the person with cancer is facing and **try not to take criticism or aggression too personally**.
- Try to resist the temptation to do too much for the person with cancer. It's important that they **maintain as much independence and dignity as possible**. Allowing them to continue doing some jobs and keep some responsibilities is likely to help you and ensure they keep some control over their life.
- **Eat regular, balanced meals** – this will help to keep your energy levels up.
- Remember that having **'time out' or 'respite' of your own is important**. Often the best way to look after the patient is to look after yourself. Try not to feel guilty about it. Instead, view it as an investment into your ability to keep on caring.
- **Identify type of activities that give you pleasure and help you cope and make a time to do these** activities. These might be:
 - Having a massage
 - Going to a movie
 - Seeking out opportunities to talk to other carers
- **Make time for exercise**. It's likely to help improve your health, mood and ability to sleep.
- Seek out opportunities to help you **maintain your own identity**. It's important not to become solely "the relative/carer/friend of the person with cancer". You may like to set boundaries and schedule activities where caring for the person with cancer is not the focus. For example, *"when I'm at tennis I don't talk about cancer"*.
- Try not to feel guilty about considering cancer-related decisions in terms of *"what is good for US"*, rather than just *"what is good for THE PATIENT"*.
- Remember that you're doing the best you can and there are **some things that you won't be able to change**.
- If your role is getting you down, **speak to your doctor**. They may be able to prescribe some medication, or refer you to someone to speak to about what you're experiencing.
- If you're feeling overwhelmed, **write down all of the things that are worrying you**. You may then find it useful to **divide them up** into 'Things I CAN do something about in the next month' and 'Things I CAN'T do something about in the next month'. Use the sheet at the end of this section to help.

6. Coping with other people's reactions and expectations (e.g. offers to help and updates on progress)

You may find the reactions of others draining. It's okay for you to put limits on your interaction with others. One way to do this is to **ask people to send you messages of support via email or text message** rather than by telephone. Then you can receive and respond to them when you have time and you feel up to it.

If you choose to return people's calls but they don't answer, **leave a detailed message** on their voicemail/answering machine so that they feel informed, but don't need to ring you back.

You may find it helpful to **appoint a 'help coordinator'** who manages your offers of help and delegates tasks to appropriate individuals. It's often easier for someone slightly removed from your situation to do this, particularly if, as typically happens, offers of help decline with time but your need for help doesn't.

Consider **delegating the task of keeping others up to date with the patient's progress to one close, but more removed, contact person** (e.g. a close friend, brother, sister). That way, if things get difficult or change quickly, you only have to speak to one person.

If you don't want to/aren't able to ask someone else to help keep everyone up to date, consider sending out **text messages to multiple people**. You could also consider using the "I'm thinking of you" website. This is an **internet-based service using email and SMS technology** to link family, friends and communities in times of need. For further information, visit www.imthinkingofyou.com.au.

Often people want to help, but don't know what to say or do, so don't be afraid to be direct with people in letting them know how you would like them to treat you (and/or your children if relevant).

7. How to cope with the waiting

Here are some ideas to consider which might make waiting more bearable.

- Take a book/ radio/ iPod/ MP3 player/ **something to do/read/listen to**.
- Pack some **snacks and a drink**.
- Visit www.cityofadelaide.com.au to find out what is happening in Adelaide.
- If you are at a hospital in the city, consider having a look around the city on the **free bus**. For a map and more information, visit www.cityofadelaide.com.au/assets/coa/Info/adelaide_connector.pdf.

8. Managing the person with cancer's diet

This can be a daunting task that often falls upon carers, family members and friends. What a person with cancer should eat depends on whether or not they are undergoing treatment (see links below). However, the following general guidelines may be of assistance. If you are not sure, contact the **Cancer Council Helpline** (phone 13 11 20), your **doctor** or a **dietician** for advice.

- Encourage them to **drink plenty of fluids**. It is best to avoid fizzy drinks as this may reduce appetite. Caffeine can interfere with sleep. Using straws or freezing drinks in ice cube trays can help increase fluid intake.
- If nauseous, **avoid greasy, fatty, sweet foods or anything with a strong odour**. Favourite meals should also be avoided at this time because a permanent distaste for them may develop.

- In the case of a sore mouth or throat, **avoid citrus fruit/juice, spicy, salty, rough, course or dry foods. Cook foods until tender** – soft foods may be easier to eat. Mixing them with butter/gravy/sauces will make them easier to swallow. Serve food cold or at room temperature. They could also ask their doctor about numbing agents to take before meals.
- **Food hygiene is very important.** Where possible, avoid pre-made food from salad bars or unpasteurized milks and juices, wash all food and utensils thoroughly, cook meat well and store food at low temperatures.
- Encourage the person with cancer to ask their doctor or dietician whether **nutritional supplements** are necessary.

Additional resources on eating/food:

- For Cancer Council SA's resource "**Nutrition for People Having Cancer Treatment**", visit www.cancersa.org.au.
- For information on **what to eat after colon surgery** from the Dana-Farber Cancer Institute, visit <http://www.dana-farber.org/Health-Library/Eating-after-colon-surgery.aspx>.

9. Dealing with treatment side effects

It's important that treatment side effects are discussed with a doctor. Effective methods of controlling or minimising many side effects do exist – there's no need for the patient to just "put up" with it all.

With the patient's permission, **ask their doctor what sorts of side effects or symptoms you should be concerned about when they get home and what to do if the patient experiences them.** For example, the treating team may have a 24-hour number you can ring for advice or the doctor may suggest ringing 000.

The nurses on the **Cancer Council Helpline** (phone 13 11 20) may be able to provide some general advice on how to manage.

Healthdirect Australia is a 24-hour health advice line (phone 1800 022 222) staffed by registered nurses who may also be able to provide you with information and advice.

The patient may benefit from attending a "**Look Good... Feel Better**" workshop to help them deal with the appearance-related side effects of chemotherapy and radiotherapy such as hair loss and changes to the skin.

Alternatively, even though individual's reactions differ significantly, the following links and fact sheets may provide some useful tips:

- For information from Cancer Council SA on **managing the side effects of treatment**, visit http://www.cancersa.org.au/asp/side_effects.aspx.
- For information from Macmillan (a UK-based cancer support organisation) on **managing side effects of treatment**, visit <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Symptomssideeffects.aspx>.
- For information from Cancer Council SA on **nutrition for people having cancer treatment**, visit http://www.cancersa.org.au/resource_library/3/16/Nutrition_people_having_cancer_treatment_May2007.pdf.
- For information from Cancer Council SA on **oral health during cancer treatment**, visit http://www.cancersa.org.au/resource_library/3/17/Oral_health_Sept2007.pdf.
- For information from Cancer Council SA on **skin care during cancer treatment**, visit http://www.cancersa.org.au/resource_library/3/17/Skin_care_during_cancer_treatment.pdf.

- For information from Cancer Council SA on **understanding and controlling cancer pain**, visit http://www.cancersa.org.au/resource_library/3/16/Understanding_cancer_pain_Nov2007.pdf.
- For information from Cancer Council SA on **hair loss**, visit http://www.cancersa.org.au/resource_library/3/16/Hair_loss.pdf.

10. Other practical issues

Getting to Adelaide

Community Passenger Networks

Some parts of rural South Australia have community passenger networks that may be able to help you get to and from Adelaide. For help with making travel arrangements and more information, contact your local office

- **Barossa Regional Community Transport Scheme** (Nuriootpa, (08) 8563 8411)
- **Eyre Peninsula Community Transport Network** (Port Lincoln, (08) 8683 0551)
- **Hills Community Transport** (Mount Barker, (08) 8391 7234)
- **Kangaroo Island Community Passenger Network** (Kingscote, (08) 8553 4500)
- **Mid North Regional Passenger Transport Service** (Clare, (08) 8842 1677 or 0400691167)
- **Murray Mallee Community Transport Scheme** (Tailem Bend, (08) 8572 4288)
- **Northern Passenger Transport Network** (Melrose, (08) 8666 2255)
- **Riverland Community Transport Scheme** (Berri, 1800 334 882)
- **South East Community Passenger Network** (Mt Gambier, (08) 8725 3622 or (08) 8724 9020)
- **Southern Communities Transport Scheme** (Victor Harbor, (08) 8551 0760)
- **Yorke Peninsula Community Transport** (Minlaton, 1300 132 932)
- **Coorong Coaches Medical Service** (Keith, (08) 8755 3307)

Bus and ferry services

For information on regional bus services and links to timetables visit www.bussa.com.au Alternatively, the following information about bus and ferry companies that travel to and from Adelaide may be helpful.

- **Premier Stateliner Coach Group:** (08) 8415 5555 www.premierstateliner.com.au
Travels to and from Port Augusta, Whyalla, Port Pirie, Port Lincoln, Eyre Peninsula, West Coast, Riverland, South East, Fleurieu Peninsula
- **Yorke Peninsula Coaches:** (08) 8821 2755, www.yppoaches.com.au
Travels to and from Moonta, Kadina, Wallaroo, Clare, Jamestown, Peterborough
- **Buses R Us:** (08) 8285 6900, www.busesrus.com.au
Travels to and from Broken Hill, Mildura
- **Greyhound Australia:** 1300 473 946, www.greyhound.com.au
Travels to and from Coober Pedy, Olympic Village, Woomera, Pimba, Mildura, Alice Springs
- **LinkSA/ Transitplus/ Barossa Valley Coaches:** (08) 8339 7544, www.linksa.com.au
Travels to and from Adelaide Hills, Barossa Valley Region, Mid Murray Region, Murraylands Region, Angle Vale Region, Victor Harbor Region
- **SeaLink Kangaroo Island Shuttle Service:** 131 301, www.sealink.com.au
Within Kangaroo Island buses run from Penneshaw, Kingscote and American River. A bus also runs from Adelaide to Cape Jervis
- **Townsend Riverland Tours:** (08) 8586 6333, www.townsendstravel.com.au
Local bus through Riverland- not to Adelaide
- **SeaLink Ferry:** 131 301, www.sealink.com.au
Cape Jervis- Penneshaw

- **Sea SA:** (08) 8823 0707, www.seasa.com.au
Wallaroo-Lucky Bay

Air services

- **Regional Express (REX):** 131 713, www.rex.com.au
Travels to and from Adelaide, Cooper Pedy, Ceduna, Whyalla, Port Lincoln, Kingscote, Broken Hill, Mount Gambier.
- **Sharp Airlines:** 1300 556 694, www.sharpairlines.com
Travels to and from Adelaide, Port Augusta, Hamilton, Portland.
- **Qantas:** 131 313, www.qantas.com.au
Travels to and from Adelaide, Olympic Dam, Port Lincoln, Mildura.

Travelling by car

For directions, visit <http://maps.google.com.au/>.

Getting from the bus station to your accommodation

The central bus station is located at 85 Franklin Street/84 Grote Steet, Adelaide (it runs between both streets). To get to your accommodation, you could:

1. Catch a **taxi** - these can be hailed just outside the terminal.
2. Catch a **bus**. For further information, visit www.adelaidemetro.com.au.

Getting from the airport to your accommodation

To get to your accommodation, you could:

1. Line up outside the airport terminal at the taxi rank and hail a taxi by raising your hand.
2. Catch the **Skylink Shuttle** (phone: 1300 383 783 7:00am-8:00pm or visit www.skylinkadelaide.com) to the city and (if necessary) catch a taxi from there. It is worth noting that the Skylink Shuttle pick up location at the airport is a 5-10 minute walk from where you will exit the terminal if you're on a Regional Express (REX) flight, but it's close to the exit for Qantas or Sharp Airlines flights.
3. Catch the public **JetBus** service (routes J1 and J2). The pickup and drop off location is to the left as you exit the main terminal. These buses travel to the city, Glenelg and the north-eastern suburbs. You can purchase tickets from the driver when you board the bus. For further information visit www.adelaidemetro.com.au/routes/jetbus.
4. If you're being picked up by a family member or friend and you're flying on REX, remember to tell them that the REX pickup area is located outside the old international terminal area, not outside the main terminal (300m away). To get to it, your driver will need to take the 'Bus/Limousine' lane instead of the 'Arrivals' lane when approaching the terminal.

Getting to treatment

Getting to the hospital for treatment or appointments can be difficult as PATS will not cover the cost of taxis. If you don't have access to a car or someone to take you, you may need to consider one of the following options:

- **Cancer Council SA Bus Service** If staying at a Cancer Council Lodge, a bus service is available to take you (and your carer if space permits) to and from Cancer Council Lodge (Greenhill) and Cancer Council Lodge (Flinders) to the Royal Adelaide Hospital, St Andrews

or the Flinders Medical Centre. The service runs several times a day. To book a seat, speak to reception when you arrive at the Lodge.

Visit the Country Cancer Support website to **watch a video** where John shows you how to catch one of the Cancer Council SA buses described above and what to expect along the way.

- **Leukaemia Foundation Patient Transport Program** (phone (08) 8100 9400 or 1800 620 420) If you have a blood cancer and access to ongoing transport is a problem, trained volunteers are available to take you to and from treatment, free of charge in a Leukaemia Foundation car. Bookings essential.
- **Red Cross Transport Scheme** (phone 1800 246 850 or (08) 8100 4500) If you do not have access to other means of transport to attend medical appointments, this service may be able to help. Carers can travel with clients. Ring to discuss your situation and to find out how to register and what it costs.
- **The Queen Elizabeth Hospital Transport/Lyell McEwin Hospital Transport** If you are in receipt of an old age or disability pension and have no other means of transport, speak to your treating team at TQEH or Lyell McEwin Hospital about travel options. If you are eligible, they may be able to provide you with taxi vouchers to cover the costs of travelling from your accommodation to the hospital (and return) or have a volunteer driver take you. This service is not available for transport to and from the airport/bus station or railway station.
- **Public transport** For information on bus, tram and train routes, visit www.adelaidemetro.com.au. Enter your departure and destination street addresses and find out which services are relevant to you. You can also ring the Adelaide Metro Info Line toll free on 1800 182 160 between 7am and 8pm. Remember that services don't run as frequently over weekends as they do during the week. To make it obvious to the driver that you would like to be picked up, raise your arm when the bus/tram/train is approaching.
 - **Buses** – once on board, you can buy a ticket from the driver. If you have a Seniors Card you are eligible to travel free of charge between 9.01am and 3pm on weekdays and at any time on weekends or public holidays. Show the driver your Seniors Card to obtain your free, green ticket. Alternatively, have small change and any other concession cards you hold ready to give to the driver. You will then need to put your ticket in a blue or yellow machine (with the arrows on the ticket facing towards the machine) to validate it before you sit down. If you have any questions, just ask the driver. Remember to press the red button or pull the blue string near the window to let the driver know when you would like to get off at the next stop.
 - **Trams** – once on board, you can buy a ticket from the conductor. If you have a Seniors Card you are eligible to travel free of charge between 9.01am and 3pm on weekdays and at any time on weekends or public holidays. Show the conductor your Seniors Card to obtain this free, green ticket. Alternatively, have small change and any other concessions cards you hold ready to present. You will then need to put your ticket in a machine to validate it before you sit down. If you have any questions just ask the conductor. Remember to press the button to let the driver know when you would like to get off at the next stop.
 - **Trains** – once on board, you can buy a ticket from a machine. Please have small change ready and carry your concession cards with you at all times. An inspector may ask you to show these if you have bought a concession fare. After purchasing your ticket, validate it in a machine before you sit down. If you don't have the correct change or the ticket machine isn't working, you can buy a ticket when you get off the train, before you depart the train station. If you are considering catching the train to the Lyell McEwin Hospital (Adelaide to Gawler Central Line), be aware that the Nurlutta station is approximately 2km from the hospital, so if you have difficulty walking you may prefer to travel by bus.
- **Taxis** When you ring to book you will need to be able to tell them your pick up address, pick up time and the address of the destination you would like to go. Most hospitals have a taxi rank near their entrance or will be happy to call one for you when you are leaving.

- Adelaide Independent Taxi Service, phone 13 22 11
 - Suburban Taxi Telephone, phone 13 10 08
 - Yellow Cab Co Telephone, phone 13 22 27
- **Driving and parking your own car** Whilst parking is available at most hospitals, it can be expensive. If you are attending a public hospital and need to stay more than two hours, parking on hospital grounds comes at a cost. However, if you need to attend a public hospital on a regular basis (e.g. for chemotherapy or radiotherapy), speak to your treating team about how they may be able to help you cover the costs of parking. For example, at the Lyell McEwin Hospital permits are issued to eligible patients attending regular treatment appointments and at TQEH, arrangements can be made for eligible patients' parking fees to be waived whilst undergoing treatment. Commercial car parks are available at the RAH and Flinders Medical Centre. If you aren't eligible for assistance outlined above, it may be worth asking if you can negotiate a weekly rate.
 - **Walking** If you (or your carer) choose to walk to your hospital, take care to walk in well-lit areas, particularly if you are walking through the parklands on the fringe of the city after dark

Getting around in Adelaide

- **See above for information on public transport** or visit www.adelaidemetro.com.au.
- **Taxis** When you ring to book you will need to be able to tell them your pick up address, pick up time and the address of the destination you would like to go. Most hospitals have a taxi rank near their entrance or will be happy to call one for you when you are leaving.
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- **Walking** If you (or your carer) choose to walk to your hospital, take care to walk in well-lit areas, particularly if you are walking through the parklands on the fringe of the city after dark.

Emergency phone numbers

- **In an emergency, phone 000.** It's best to call this number and get an ambulance on its way as soon as possible, rather than trying to contact your doctors for advice which may take some time.
- For police assistance with non-urgent crime, phone 131 444.

Shopping

Although there are some exceptions (for example some supermarkets), shopping hours in Adelaide are generally 9am-5pm Monday-Friday, 9am-5pm on Saturday and 11am-5pm on Sunday. In the suburbs, most shops are open until 9pm on Thursday nights. On Fridays, city stores are open until 9pm.

- For information on shops that are close to you, **ask at the reception desk** of your accommodation facility.

- Alternatively, to use **Google maps to help you find local services/shops**, visit <http://maps.google.com.au/> and type in what you are looking for and the suburb and state in which you are located (e.g. “chemist near Eastwood, SA”, “ATM near Wayville, SA”, “service station near North Adelaide, SA” or “supermarket near Salisbury, SA”).
- To use **Yellow Pages** to help you find local services, visit www.yellowpages.com.au/.
- To find your **local takeaway outlets**, visit www.findtakeaway.com.au/.
- To find your **local IGA supermarket**, visit <http://iga.dynamiccatalogue.com.au/portal/storelocator>.
- To find your **local Foodland supermarket**, visit www.foodlandsa.com.au/internet/store-locator.html.

Financial issues

- Speak to the **social worker in your hospital** about your situation to see if they know of any financial assistance schemes for which you may be eligible.
- Ring the Cancer Council Helpline (13 11 20) to find out more about the **Cancer Council SA Legal and Financial Planning Service** and the **Financial Assistance Program**.
- Find out from **Centrelink** if you're eligible for the disability support pension, mobility allowances, carer payments, carer allowances and/or sickness allowances by phoning 132 717 or visiting www.humanservices.gov.au
- Make sure you claim your travel expenses through **PATS** (if eligible).
- Speak to your **utility providers** (e.g. gas, water, electricity) about your situation. They often make allowances for people experiencing financial hardship by extending the amount of time you have to pay your bills. Banks and other lenders may also be prepared to make adjustments (for example by allowing you to defer or reduce loan repayments).
- Speak to your **superannuation fund** to find out if you are eligible to access superannuation early.
- Phone the **National Financial Counselling Hotline** on 1800 007 007 between 9am and 5pm for free financial advice.
- Visit www.moneysmart.gov.au for a list of free financial counselling services.
- Visit www.medicareaustralia.gov.au or phone 132 011 for advice on what is covered and how much you'll be reimbursed for your medical expenses.

Legal issues

Being given a diagnosis of cancer can raise several legal issues, for example the need to develop or revise a will, organise power of attorney and deal with issues such as superannuation, insurance, work and compensation. Dealing with these issues can be overwhelming, but fortunately, help is available.

A useful place to start is to read the general guide developed by Cancer Council Victoria about legal rights and responsibilities in the context of a cancer diagnosis. You will find this by visiting www.cancervic.org.au/about-cancer/living-with-cancer/legal-rights-and-responsibilities.

Please note that as this guide has been written in Victoria, some differences in laws may apply. Be aware that this resource is not intended to take the place of professional legal advice.

You could also:

- Ring the Cancer Council Helpline (13 11 20) to find out more about the **Cancer Council SA Legal and Financial Planning Service**. They may be able to assist with legal issues such as drafting wills, powers of attorney, tenancy disputes, insurance claims and disputes.
- Contact the **Legal Services Commission of South Australia** for online information about a range legal issues by visiting www.lsc.sa.gov.au/ or phoning the Legal Help Line on 1300 366 424 (Monday-Friday, 9am-4.30am).
- Visit your local **Community Legal Centres** (CLCs). These are not for profit, non-government organisations that provide legal and welfare services. Offices are located in the following rural locations in or near South Australia:

- **Berri** (also covers Loxton, Renmark and Waikerie), Riverland Community Legal Service, phone (08) 8582 2255 or visit www.ozland.net.au/~rcls.
- **Broken Hill** (also covers Wilcannia, Wentworth, Tibooburra, White Cliffs, Wanaaring and Ivanhoe), Far West Community Legal Centre, phone (08) 8088 2020 or 1800 300 036 or visit www.farwestclc.org.au.
- **Mildura**, Murray Mallee Community Legal Service, phone 1800 243 002.
- **Mount Gambier** (also covers Keith, Robe, Bordertown, Kingston, Naracoorte and Millicent), South East Community Legal Service, phone 1300 369 236.
- **Port Augusta** (also covers Coober Pedy, Oodnadatta, Leigh Creek and Nepabunna), Women's Legal Service (SA), phone (08) 8641 3366 or 1800 555 850.
- **Port Pirie** (also covers Clare, Kadina, Maitland, Peterborough and Port Augusta), Westside Community Lawyers Inc, phone (08) 8633 8929 or 1800 114 44.
- Find a lawyer who specialises in your area of need and is located in an appropriate geographic location by using **The Law Society of South Australia's Legal Referral Service**. To use this free online tool, visit www.lawsocietysa.asn.au/referral/LSSA_SearchCriteria.asp.

11. Support services that may be helpful

Don't be afraid to seek help of any description. Many people report that they wish they sought emotional help earlier. The following services may be of use.

- **Cancer Council Helpline** (phone 13 11 20) For confidential information and support for people with cancer, their families and their friends, from nurses who have a background in oncology.
- **Carer Advisory and Counselling Service** (phone 1800 242 636, visit www.carers-sa.asn.au or email info@carers-sa.asn.au) for information, emotional support, financial assistance and free counselling for carers.
- Visit or phone your local **CarersSA** office:
 - Loxton (phone 1800 806 580), River Murray and Mallee Carers
 - Port Lincoln (phone 1800 350 004), Eyre Carers
 - Mount Gambier (phone 1800 654 429), South East Carers (co-located with the Commonwealth Respite and Carelink Centre)
 - Port Augusta (phone (08) 8641 1844), Northern Country Carers
- **Health Direct Australia** (phone 1800 022 222) for 24 hour health advice.
- **Palliative Care Council of SA** (phone 1800 660 055 or visit www.pallcare.asn.au) for information on caring for a palliative patient at home.

For information on and assistance with organising respite care for a few hours or a few days, contact:

- **Commonwealth Carer Respite Centre** (phone 1800 059 059)
- **Commonwealth Carelink Centres** (phone 1800 052 222)

For information on **eligibility for pensions, allowances and payments** (for you and/or the patient), phone 132 717 or visit www.humanservices.gov.au.

Use the 'Find help near you' page on the Country Cancer Support website **to find support services in your local area**.

12. Coping with the loss of a loved one

The emotional pain and upheaval after the death of someone you love can feel unbearable. Although things may never be quite the same, fortunately, with time, this pain usually does begin to heal.

While everyone is likely to experience grief differently, one way to understand the grief process is through the **'tasks of grief'** model. This approach states that to cope effectively with a loss, we must do the following:

1. **Accept the reality of the loss.**
2. **Experience the pain of grief** (it isn't helpful or possible to try to avoid feelings of grief forever).
3. **Adjust to the new environment where the deceased person is missing** (this includes adjusting to practical changes to our life, changes to responsibilities and changes to how we view ourselves and the world).
4. **Reinvest in life and the present moment and create a new type of relationship with the deceased based on your memories of them and their spirit and love** (acknowledging the relationship you had with them in the past, understanding that you don't need to forget them, but that it is okay to connect with other people and the world the way it is now).

The following strategies may help you achieve these 'tasks':

- Put aside some time each day to quietly reflect and fully experience your emotions.
- Allow yourself to cry.
- Find a few people who are good listeners and who you can share your feelings and experiences with. These may be friends, family, professionals or a mixture. As previously stated, expressing this grief is likely to help you to understand, accept and adjust to your losses.
- Keep a diary of what you're thinking and how you're feeling. Having a record of this journey may be interesting to look back on and examine your progress.
- Make the effort to see some close friends or family – this is likely to improve your mood.
- Avoid making important, major decisions soon after your loss.
- Seek professional help (with things as varied as finances, jobs around the house or coping emotionally) – you don't need to do this alone.
- Don't be afraid to talk about the person who has died. While this can be difficult at first, it's likely to help you and the people around you adjust.
- Write to the person who has died and tell them how you feel and what you're thinking.
- Make a memorial – you could do this by planting a tree, making a photo album or putting some of their special possessions together in a box.
- Don't be afraid to remember and celebrate the person who has died on special days such as their birthday.
- Learning relaxation, scheduling activities that are consistent with your values and problem solving may also be useful strategies to help you cope. See the 'Practical tips for dealing with difficult emotions' section of the Country Cancer Support website for further information on how to do this.

If you find that this is too difficult to do and that grief is enduring and interfering with your quality of life, consider speaking to your GP or a counsellor or psychologist who is trained to provide strategies to help you with the necessary adjustment. When grief isn't resolved it can lead to depression, so seeking help early is important.

13. Additional online resources

- For information on **resources for children who know someone with cancer** (Cancer Council SA), visit www.cancersa.org.au/resource_library/3/18/Someone_I_know_has_cancer_April2008.pdf.
- For information for **people caring for someone with advanced cancer** (Cancer Council SA), visit www.cancersa.org.au/resource_library/3/18/Caring_for_the_person_Jul09.pdf.
- For information for people who **want to help someone affected by cancer** (Cancer Council SA), visit www.cancersa.org.au/resource_library/3/18/I_want_to_help.pdf.
- For **information for carers** (UK-based cancer support organisation MacMillan), visit www.macmillan.org.uk/Cancerinformation/Cancerinformation.aspx and click on “If someone else has cancer” then “Caring for someone with cancer”, “Caring for someone with advanced cancer”, “Young carers” or “Working while caring for someone”.
- For **information for employees who are carers and also working in paid employment and their employers**, visit www.workingcarers.org.au/.
- For online **information and support for carers who are under 25 years**, visit www.youngcarers.net.au.
- To find out information about **palliative care services**, visit www.caresearch.com.au.
- Information for those **bereaved and grieving, their carers, friends and colleagues, and health and welfare workers** can be found at www.grieflink.org.au.

Coping with stress and anxiety



Country
Cancer
Support
South Australia

Working out how to best help yourself

Sometimes taking control of problems or worries can seem like an overwhelming task. If you feel that you have a number of things you need to deal with, but don't know where to start, using this chart may help.

Notice the worry



Ask yourself exactly what you are worrying about



Write these worries down into two lists



Things I CAN do something about in the next month (E.g. Working out how I will get to Adelaide for my next check-up)



Learn how to address these concerns using a structured problem solving approach, the calming technique and relaxation (see other worksheets on the website)

Things I CAN'T directly do something about in the next month (E.g. Worrying that my cancer will return)



Learn strategies to help you let worries go, calm down and relax

(see other worksheets on the website)