



3. SOCIAL NEEDS

A person soldiering on with advanced cancer may tell you they depend on good doctors, latest treatments and a positive frame of mind. But it is more likely they will dwell on the support they have received from family, friends, their community, their church, their beliefs – or the lot.

A life-changing illness can add new weight to social, cultural and spiritual connections. Strong networks, effective communication and spiritual fulfilment can all help to make life that little bit easier.

Social support

A good social support network usually includes family, friends, community members and others who provide physical, practical and emotional help.

Just as individuals need different levels of social support, people around them are likely to react to those needs in different ways. Some people have family and friends who rally around and cannot do enough for them. Others find the people they most depend on withdraw because it is all too distressing for them, or they do not know how to help.



FACT

People with advanced cancer and their caregivers, who feel that they have a good support network tend to cope better with their diagnosis and generally have a better quality of life than those who do not have such back-up.^{50,51}

What may help

Make contact

A variety of groups and services offer support for people with advanced cancer, their caregivers, family and friends. These include face-to-face groups, or email and telephone contact, especially for people who live in rural areas or are less mobile.



You may start with the Cancer Council's services (**phone 13 11 20**), enquire about the Cancer Connect program, state-based and cancer-specific support groups and its Helpline.

Contact your hospital or talk to your cancer nurse or a social worker to get more information about other local support groups.

Carers Australia, has information on carer support groups around Australia. Contact **Freecall 1800 242 636** for information, or for over-the-phone counselling and support.

Accept help

Try not to let your pride or reluctance to “impose” stop you from accepting help. Most offers of assistance, especially from those close to you, are genuine. In many cases, this is their way of letting you know you are not alone.

Family or friends may be able to pick up medications, cook or simply sit with you. Hopefully they will appreciate your honesty when you really want to be alone or want to do something for yourself. But, for the most part, their help may in fact be helpful to all of you, including them.



• If you want to help someone who may be reluctant to accept it, specific offers (“Tell me what I need to pick up from the chemist”) are often more effective than “open” offers (“What can I do to help?”)

Relationships

Advanced cancer takes its toll on all of those concerned and relationships are often affected. As your physical abilities change, the role you play in the household and within your family may change. Also, you and those you love may experience emotional ups and downs that are not likely to be synchronised with each other.

While the strain may widen existing cracks in relationships, times such as this often bring out the best in people and strengthen the bonds between them. This usually takes work, though.



FACT

“Studies of couples where one partner has a life-threatening disease show that good relationships generally stay good and the less strong ones continue to be less strong.”

(Source: Cancer Council Victoria, Advanced Cancer – Emotional Impact, www.cancervic.org.au)

What may help

Talk to each other

Openness and honesty about how you are feeling and what you need from each other often works best. For instance it might be difficult to tell your partner that they are stifling you with too much attention is likely to be far less damaging than the frustration and resentment that may build up otherwise.

Talk to others

Talking about relationship matters with others in a similar situation may help you see things more clearly or give you a few hints. [Cancer Connect \(13 11 20\)](#) can put you in touch with support groups in your area.

See a counsellor

Ask your doctor to refer you to a counsellor who may help you – and, where appropriate, the people you love – work through your feelings.

Talking to family and friends

As hard as it may be to deal with your diagnosis, it is important to talk to others about what is happening and the uncertainty the future now brings. Your family and friends may worry about you and want to know how you are feeling and how they can help.

Discussing the progression of your illness and even end of life decisions may be draining, but avoiding the subject only makes it harder to cope. Indeed, talking about your feelings, hopes and dreams can be healing and comforting.

From a practical perspective, the people around you need to understand your needs, plans and wishes, especially if you are likely to get to a point where you cannot make decisions for yourself.

Regardless of their reaction, talking openly and honestly in an age-appropriate way will assist them to understand your illness.

What may help

Plan your chat

Think about what you want to say and how you will respond to questions. You may find it useful to write this down and refer to it during your interactions. Find a quiet time when you are least likely to be interrupted and ensure that is also a good time for the person you want to speak to. The last thing you want is to have this conversation with someone who is tired and stressed.



tips

When discussing your diagnosis and illness with those around you:

- Speak from the heart – use direct language that describes how you are feeling.
- Allow time for the other person to talk, in case they want to

ask questions or discuss their own feelings.

- Don't try to cover everything – there is probably much to discuss, but you may need to allow time for bits of information to digest.

Telling the children

As for “telling the kids”, that is never going to be easy for either you or them, but do not be tempted to shield them from upsetting news. Children often know when there is something wrong and may immediately think the worst.

Children and teenagers may react to the news in different ways, whether it be anger, confusion, sadness⁵² or denial. Plan what you want to tell them and deliver the news in a language they can understand. Young children can be confused by too much information, whereas emotionally mature teenagers may feel they are left hanging with too little information.

tips

When discussing your diagnosis and illness with children and teenagers:

- Always be honest – in times of uncertainty, honesty is often the one thing children can depend on.
- Encourage them to ask questions and answer them as fully as you can.
- Explain the impact on them – children and most teenagers are

fairly ego-centric and need to know how their everyday lives will be affected.

- Be as positive as possible but avoid making promises.⁹²
- Listen to their thoughts and feelings without judgement.

Talk to a professional

If you need assistance talking to your family and friends, counselling from a mental health professional may help. If you do not want or need professional help, your carer, family or friends can always make appointments for themselves.

Take the lead

Some of your family, friends or colleagues may be unsure of how to talk with you. They may be worried about saying the wrong thing or about whether they should mention your illness.

It may pay for you to take the lead. Acknowledge your illness with them and give them some tips on how you wish to be treated, and what you are happy to talk about with them and when. Many people with advanced cancer say this openness often relieves the awkwardness.

For more information

- The Cancer Council has a booklet, *When a Parent Has Cancer: How to Talk to Your Kids*, which is not specific to advanced cancer but contains useful information. Go to www.cancercouncil.com.au to download a copy, or **call 13 11 20** to have it sent to you.
- The **US National Cancer Institute** has helpful information about talking with partners and children. Go to www.cancer.gov/cancertopics/advancedcancer
- A US website, **Cancer Care**, also has information about communicating with family. Go to www.cancercare.org

Talking to health professionals

It may not always be easy to open up to your health professionals. You may feel you are taking up too much of their time or that you have bent their ear once too often. Regardless of how busy they are, doctors, oncologists, and other health professionals would rather have too much information from you than not enough.

Research consistently shows that good communication between patients and their health care teams not only improves patient satisfaction with care, but also improves their quality of care.⁸²

What may help

Ask questions

It is important that you understand the information given to you by your health care team. It may help to write down your questions so you do not forget to ask them. Don't be afraid to ask what you might think are "dumb" questions – they

are often the best ones. You do not want your health care team to make incorrect assumptions about what you know because you are not communicating openly with them.

Take notes of the answers to your questions, especially if it is detailed information. If you are feeling emotional, shell-shocked or overwhelmed or if you did not understand what your doctor said, ask them to repeat or write down for you some key words that will help you to remember what was discussed in case you need it. Your doctor may also be happy for you to tape your discussions. Patients often report finding such tapes very helpful to listen to again after the consultation and also help their family to better understand what is going on.⁹⁴

Know who to contact

People with advanced cancer and their carers often say they don't feel comfortable calling their doctor with questions between visits, or that they are not sure their doctor is the person they should be asking.

During a consultation, ask your doctor who you should contact regarding specific matters, such as mobility aids, respite care or emotional support. They may also be able to tell you who to call for after hours help.

tips

- For effective communication with your health care team:
 - Be prepared with a list of questions, or write them down as you think of them during the visit. Some people say they often do not know which questions to ask – use this booklet as a guide to help you identify areas that you may want to know more about.
 - Book a longer consultation if you know you have a lot to talk about. That will help you and your doctor to feel less rushed.
 - Take along a friend or family member to help you absorb the information and ask the necessary questions.
 - Take notes and ask for clarifications, in plain English, of anything you don't understand.

For more information

- Palliative Care Australia's free booklet *Asking Questions Can Help: An Aid for People Seeing the Palliative Care Team* lists questions you may like to ask your doctor. Phone **Palliative Care Australia** on **(02) 6232 4433** or go to www.palliativecare.org.au

- The Cancer Institute NSW has brochures about asking questions of your haematologist, medical oncologist and surgeon.
Go to www.cancerinstitute.org.au/cancer_inst/patients/questions.html

Cultural differences

Australia is a multicultural country filled with diverse groups of people whose collective beliefs and values guide different types of thinking and behaviour.⁵³

As such, cultural requirements and sensitivities are important considerations in the care of people with advanced cancer.

What do you want to know about your illness? What does your family need to know? What level of treatment is acceptable? How do you talk about death? These are some points of cultural difference that, with the right communication, can be integrated into your care.

What may help

Talk to your Doctor

Talk to your Doctor and other health care providers about customs or family traditions that they may need to consider. This may be as simple as working around prayer times, or as detailed as instructing them on how to handle a body after death.

Call on your community

You may like to enlist the help of family members, friends or others from your cultural community in ensuring your beliefs and customs are respected. If you are unwilling or unable to assert your wishes, they can step in on your behalf.

Language barriers

Comprehending a diagnosis of advanced cancer and a raft of treatment options can be daunting for the most proficient of English speakers. So if you have difficulties with written or spoken English you may not only misunderstand what you have been told about your illness, but also miss out on additional useful information and services.

It is very important, if English or literacy is not your strength, to seek help in finding and interpreting information related to your illness.

What may help

Talk to your Doctor

If English is your second language, ask your doctor or health care provider to speak more slowly, repeat information, explain colloquialisms or even write down crucial points for you.

Use an interpreter

With notice, hospitals or doctors can sometimes provide an interpreter to translate at a consultation or over the phone. If not, you may need to organise one or find a family member who can do it.

Language resources

A variety of cancer and palliative care resources are available in languages other than English:



- The Cancer Council SA has publications printed in a number of different languages.
Go to www.cancersa.org.au to download a copy or call the **Cancer Council on 13 11 20** and ask for one to be mailed to you.
- The Cancer Council Helpline offers information and support for people with cancer in Cantonese and Mandarin (1300 300 935), Greek (1300 301 449), Italian (1300 301 431) and Arabic (1300 301 625).

Interpreting services

The **Translating and Interpreting Service (13 14 50)** offers assistance with communicating in a language other than English. You can ask for a male or a female interpreter, if need be. There is a fee for some services, but communication with medical practitioners is usually free. Go to www.immi.gov.au/living-in-australia/help-with-english/help_with_translating/index.htm

Private interpreting services in your area may be found in the Yellow Pages under “Translations” and “Interpreters”.

Spirituality

A diagnosis of advanced cancer is often the cue for people to search for meaning in life. For some, this may be the first time they are confronted with the thought of death or dying.⁹⁸

People may want to understand their purpose and legacy, to celebrate their life, and look for strength, peace, harmony and comfort. They, and those around them, may change their priorities and think about what they want from life.⁵⁴

This is when spirituality, religion, faith or belief in a greater power comes into play. For some, it is an unstructured approach – spending time with others, basking in memories and reflecting on their experiences. For others, prayer, religious rites and spiritual guidance not only provide comfort and support⁵⁵, but increase their ability to cope with their illness.⁵⁶ If this applies to you:

What may help

Social and pastoral care

Social and pastoral care workers can offer support, guidance and prayer, and discuss spiritual concerns. Previous involvement, or not, in formal worship is usually unnecessary. Your local hospital or palliative care team, or your local church or religious organisation, should be able to help you find the appropriate people.

Finding meaning

Searching for meaning or finding that one's life has order and purpose has been shown to influence satisfaction with life and well-being.⁹⁸ Every person is different, but some people have found that going through old photos, writing down memories, or leaving a lasting legacy such as a taped or written message for a child, have helped them find peace and comfort. Others may find it useful to re-evaluate their priorities and goals and determine specific strategies to help achieve them.

For more information

- **Growth House Inc**, an international resource for end-of-life care, has the Handbook for Mortals, which contains a chapter on finding meaning in life. Go to www.growthhouse.org
- The US National Cancer Institute has information on looking for meaning and celebrating your life. Go to www.cancer.gov

Personal Notes

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4. LIFESTYLE

This booklet is about living with advanced cancer, including how you choose to eat, exercise, work and relax within the limitations of your illness. To try to get the most out of life, some people with advanced cancer make major changes to their lifestyle, whereas others prefer to continue on as normally as possible.