



Getting Support

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This tool has been excerpted from the TEMPO (Tailored, wEb-based, self-Management PrOgram) symptom self-management program. The content of this document has been reviewed and approved by healthcare professionals.

Knowing where to go for more support

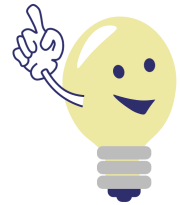
“The extent to which a person with cancer has support and feels supported has been identified as an important factor in their adjustment to the disease.”

National Breast Cancer Centre and National Cancer Control Initiative, 2003

It helps to know you will have the support you need, when you need it. While the available services and resources are extensive, they can be tricky to identify.

Suggestions for building a support team

- 1. Use the Canadian Cancer Society**– The Canadian Cancer Society has agencies in every province and territory. It can connect you to many useful resources according to your needs.
- 2. Create your support teams** – Consider who can help address your physical, emotional, financial and social needs.



We will now explain how these suggestions can help you and provide step-by-step

TOP TIP: Use the suggestion right for you:

- ✓ Read the description of each suggestion that follows
- ✓ Choose the strategy or strategies that you prefer
- ✓ Make an action plan to help you fit your preferred suggestion into your daily life
- ✓ Set rewards for the progress you make toward achieving your goal.



How can these suggestions help?

Building your support teams essentially means that you have access to supportive care that considers all aspects of your cancer experience. There are several benefits associated with this, such as:

- ✓ Reduced anxiety and depression.
 - ✓ Enhanced management of physical symptoms and side effects.
 - ✓ Increased understanding of cancer and its treatment.
 - ✓ Greater ability to cope with treatment.
 - ✓ Improved decision making and active participation in care
 - ✓ Increased satisfaction with the care provided.
 - ✓ Improved quality of life.
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Suggestion 1: Call the Canadian Cancer Society

A good place to start asking about resources in your area is the **Canadian Cancer Society** by calling **1-888-939-3333** (Monday to Friday), everywhere in Canada. You can get more information on their list of different services and resources for specific areas.

The Canadian Cancer Society can help you with:

- ✓ Cancer information service: Information about cancer, treatments, and side effects (including brochures you can request or download).
- ✓ Peer support services: information about support services in your area.
- ✓ Online community (www.CancerConnection.ca): a peer-based support service which links you to with others in similar situations.
- ✓ Information about current cancer research.
- ✓ Access to other support services in your community through their service called the “Community Services Locator”.

Suggestion 2: Create your support teams

Three main teams help you through the cancer experience. These are:

Health Care Team: Includes all the health care professionals involved in your care:	
Oncologist	Spiritual care worker
Occupational therapist	Community nurse
Oncologist surgeon	Pharmacist
Psychologist/ Counsellor	Social worker
Family doctor	Physiotherapist
Palliative care team	Dietitian
Oncology nurse	
Support Services Team: Includes all the services that might be able to help you with:	
Carer respite	Mobility
Home care	Legal services
Financial services	Support groups
Counselling	Housework
Interpreters	Accommodation
Home maintenance	Transport
Friends and Family: Includes everyone in your informal support network who might be willing and able to provide help:	
Family members	Work colleagues
Friends	Neighbours
Spiritual group members	Parents from your children's school

The first step in building your teams is to consider the type of support you need. Take some time to read through the table below to identify the services and assistance you need **now** and the areas in which you may need help over the next few months. We have suggested who is most likely to assist – you can add the names and contact details of the people and services that you deal with to create a handy reference guide.

Problem	Do I need help?	Who can help?	Name and contact details of who can help
Understanding treatment	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Nurse, family doctor, oncologist, oncology nurse, community nurse	
Treatment side effects	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Oncology nurse, family doctor, nurse, oncologist, community nurse	
Physical rehabilitation	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Physiotherapist, massage therapist, occupational therapist, nurse, community nurse	
Managing medications	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Family doctor, oncologist, nurse, community nurse, pharmacist	
Pain management	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Nurse, community nurse, family doctor	

Follow-up nursing care (e.g. dressings)	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Community nurse, nurse, family doctor	
Hygiene/ personal care (e.g. showering, wigs)	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Community nurse, community service provider	
Depression, anxiety, and/or stress	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Psychologist, psychiatrist, family doctor, counsellor, pivot nurse, social worker, family and friends	
Lack of emotional support	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Psychologist, family doctor, counsellor, social worker family and friends, community service provider	
Sexual issues	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Psychologist, counsellor, sex therapist, family doctor, nurse	
Isolation	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Family and friends, social worker, support, groups, psychologist, counsellor	
Carer needs (e.g. training in lifting)	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Social worker, community service provider	

Carer respite	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Community service provider, social worker, family and friends	
Mobility	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Physiotherapist, occupational therapist, community service provider	
Looking after children	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Family and friends, community service provider	
Dietary changes	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Dietitian	
Transport (e.g. appointments, children to school)	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Community service provider, social worker, family and friends	
Domestic help, housework, and/or home maintenance	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Community service provider, family and friends, social worker	
Preparing meals	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Community service provider, family and friends, social worker	

Shopping	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Community service provider, family and friends, social worker	
Completing forms	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Family and friends, social worker	
Accommodation	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Social worker, community service provider	
Crisis planning	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Nurse, family doctor, social worker, family and friends	
Legal issues	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>	Community legal centres, government offices, notary	
Other:	NOW <input type="checkbox"/> FUTURE <input type="checkbox"/>		

How do I build my Medical Team?

Your medical team will largely be built around you. Some members of the team will be in frequent contact (e.g. doctors). Others may only come in for a short time or you may need to ask to access to them. If you don't know who to ask about accessing additional health care services (e.g. psychologist, dietitian), a good starting point is the nurse or a social worker.

How can a social worker help?

Oncology social workers are trained to offer proper help to people with cancer and their families. Social workers can offer the following:

- ✓ Help with practical needs.
- ✓ Refer to support groups.
- ✓ Offers financial assistance and other resources such as home care and equipment, help with employer, filling out applications, money problems related to cancer, and information about health insurance.



Ask your doctor or nurse to recommend a social worker or check with the Canadian Cancer Society to put you into contact with a social worker in your area.

TOP TIP: Remember, you have the right to a second opinion on any medical issue or treatment decision. If you feel unable to work with a member of your health care team, you have the right to ask for someone else.



If you need help from someone on your medical team, but are not sure who or what to ask, **see the section 'Knowing the role of all of the health care professionals involved'** in this factsheet.

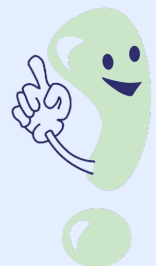
How do I build my support services team?

Once you have identified the issues you need to be addressed, you need to find out whether there are services in your area that can help.

There are many ways to find out about local services. You can:

- ✓ Ask your doctors or nurses.
- ✓ Ask your social worker.
- ✓ Ask friends and family.
- ✓ Call the Canadian Cancer Society (1-888-939-3333) and ask for the “Community Services Locator” service.
- ✓ Look through the local phone book.
- ✓ Look through the local newspaper.
- ✓ Search the Internet.
- ✓ Visit the local library.
- ✓ Contact organizations that you know – even if they do not provide the service you need, they may know who does.

TOP TIP: The Canadian Cancer Society offers a service called the “Community Services Locator” which directs you to many services according to your location and community. Whether you are the person diagnosed or a caregiver, this service will help you to find information about the many services available to you.



The service locator includes as many as 4000 services specific to cancer, for example, you can get information regarding emotional support programs, homecare, treatments, and other. You can reach this service by visiting the Canadian Cancer Society’s website: www.cancer.ca or by calling them at 1-888-939-3333.

How do I build my family and friends team?

Family and friends are a valuable source of support. Not knowing how they can help may stop some people from offering, even though they would be more than happy to do so. Unfortunately, many patients and caregivers look back and believe they took too much on themselves since they were reluctant to ask for help.

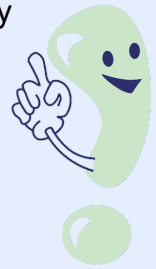
Once you have identified the help you need, consider which of your family and friends could best provide it. For example, someone with a great relationship with many of your family and friends might make an excellent contact for updates on your progress. They could then let you know who has called and you could call them back when you feel up to it.

Knowing who you can count on for what kind of help is important. Ask your family and friends to think about the help they can provide – an easy way to do so is to get them to complete a checklist like the one below.

Help I can offer	Name
<ul style="list-style-type: none">• Mow lawns• A meal prepared occasionally/nights a week/fortnight• Help with forms / other paperwork• A shoulder to cry on• Grocery shopping• Babysitting• Respite for spouse/partner• Visit you in hospital• A regular ride at a pre-assigned time (e.g. take children to school, take you shopping)	<ul style="list-style-type: none">• Communication contact point• A weekly phone call• Research information for you• Home maintenance• Run errands• Gardening• Pick up medications• Attend appointments• Clean the house• Take you out, do something social• Help with washing/ironing

Adapted from National Family Caregivers Association

TOP TIP: Talk to your family and friends about the help you might need. People often WANT to help but don't know how or don't want to impose. If family or friends offer to help, ask them how long they can do it for. Some people will be happy to help regularly for as long as it takes, others will only be able to help occasionally. It is good to know this up front.



TOP TIP: If you asked someone for help, be prepared for people who say 'no'. You do not need to take this personally. Some people might be dealing with their own problems, don't have time, don't know how to help, or have many other reasons.

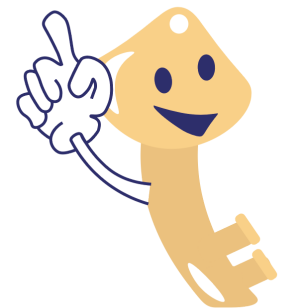
What others have said about using these strategies:

"Before I was diagnosed, I remember being amazed by the many services which were set up for cancer patients. It wasn't until I needed them that I realized the problem was not what was around, but where."

Dion, diagnosed with prostate cancer.

Key Points: Building a social network

1. Your support network might include members of your medical team, services from community-based organizations, family, and friends.
2. **Determine what type of help you need** and then find out who can provide it.
3. Your social worker and the Canadian Cancer Society can help you access a variety of services.



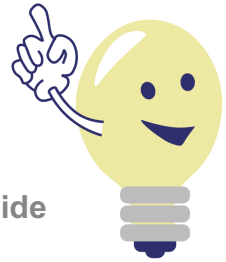
Getting emotional support

FACT: There are a number of things you can do to help you cope with your concerns and emotions. The following section takes an in-depth look at how you can seek help from others.

Suggestions for seeking support from others:

1. **Speak to your health care professionals** – Your doctors, nurses, and other members of your health care team understand that your emotional well-being is important in your ability to cope with cancer.
2. **Connect with others with similar experiences** – Although support groups or networks usually bring together people with similar experiences, your contact with others does not have to be so formal; you may find other ways of connecting through, for example, Internet forums.

We will now explain how these suggestions can help you and provide step-by-step guidance on how to use these suggestions.



TOP TIP: Use the suggestion right for you:

- ✓ Read the description of each suggestion that follows
- ✓ Choose the strategy or strategies that you prefer
- ✓ Make an action plan to help you fit your preferred suggestion into your daily life
- ✓ Set rewards for the progress you make toward achieving your goal.



How can these suggestions help?

It is important to seek extra emotional support from others when you need it because:

- ✓ Your emotional well-being is a vital part of your ability to cope with cancer and its treatment.
 - ✓ People who do not feel they are emotionally supported may feel isolated or become depressed.
 - ✓ It is reassuring to speak to people who have had similar experiences.
 - ✓ People who know what you are going through can often offer support, empathy and advice.
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Suggestion 1: Speak to your health care professionals

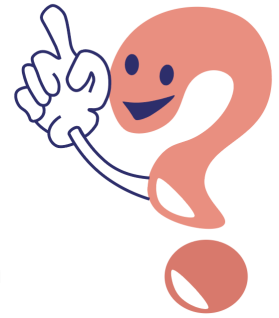
Any members of your health care team can offer you emotional support. Don't be afraid to ask – if the person you ask does not think they can provide what you need, they should be able to refer you to someone who can.

If you are unsure about who to speak to, the members of your health care team who may be more experienced with dealing with emotional issues are:

- ✓ **Nurse** — Nurses can provide you with empathy and support, and help you deal with issues that are wearing you down. They can also answer questions that might be worrying you about treatment. Nurses are an excellent starting point to help link you to the services that are available to help you address your emotional needs and concerns.
- ✓ **Psychologists or Counsellors** — Can assist you and your family to adjust to the emotional impact of cancer and treatments.
- ✓ **Social workers** — A social worker can discuss your concerns with you and help you find further support when you need it.
- ✓ **Family doctor** — Your family doctor can provide a referral to a psychologist or other mental health care professional.

How can a psychologist or counsellor help?

Psychologists and counsellors can help individuals with cancer and their families deal with significant emotional adjustment following a diagnosis of cancer, the effects of treatment, and longer lifetime adjustments. Ask your doctor or nurse if there is a psychologist you can see at the hospital/treatment centre. Your family doctor can also provide a referral to a psychologist or counsellor. The Canadian Psychological Association provides a 'Find a Psychologist' feature on their website at www.cpa.ca.



Suggestion 2: Connect with others with similar experiences

Although experiences vary between individuals, many people find it helpful to share thoughts, concerns, tips and ideas with people who are, or have been, in a similar situation. Among other things, talking to others can give you:

- ✓ Some insights into the everyday 'reality' of dealing with cancer.
- ✓ Chances to voice concerns or thoughts with others who understand from first-hand experience.
- ✓ A forum for sharing tips, hints, and ideas related to cancer and its treatment.
- ✓ An idea about what has and hasn't worked with others.
- ✓ Some handy references to good sources of assistance and information.

You can try connecting with others by:

- Joining a support group.
- Using available resources to make contact in other ways.

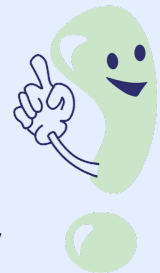
Joining a support group

Cancer support groups can be found through cancer agencies, hospitals and community organizations throughout Canada. Some are formal organizations and others are more casual groups formed by nurses, doctors, or other health workers. These peer-support groups allow patients, partners, and families to share experiences and information in a 'safe' environment. They often take the form of regular meetings 'led' by qualified health workers. Sometimes the meetings have a specific theme.

Some groups are held online and some are offered over the telephone. These forms of group contact are especially helpful for people who are geographically isolated, too unwell to travel, or do not prefer to meet face-to-face.

Where to find a cancer support group/network

While joining a support group is helpful, you may also hear about some worrying issues. If anything you hear from others worries you or raises questions, talk to your health care professional. Individual experiences can differ greatly, so try not to assume that things will happen for you just as they did for someone else.



The best way to find a support group in your region is to ask your health care professionals or check with **the Canadian Cancer Society**.

Canadian Cancer Society

The Canadian Cancer Society offers peer support in 2 different ways.

1. You can join their online community (www.cancerconnection.ca) to share experiences and build supportive relationships
2. You can choose to access their telephone peer support programs which connects you with a trained volunteer who will listen, provide hope and encouragements, and share tips to cope better. To gain access to the peer support program, you can call them at 1-888-939-3333 (toll-free) Monday to Friday.

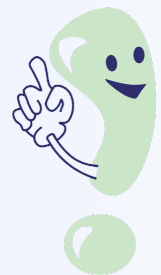
Cancer Chat Canada

Cancer Chat provides free and professionally-led online support groups for Canadians affected by cancer, including patients and those close to them. Cancer Chat online support groups are particularly suitable for those who are unable to attend a professionally-led face to face support group, because they live in a rural area or have a busy schedule of medical appointments or caregiving duties. More information about Cancer Chat Canada can be found here: <https://cancerchat.desouzainstitute.com/>.

Health care professionals

Members of the health care team may know patients, survivors, and families who are happy to talk to you about their experiences. Also, they may have anonymous stories of other patients' and partners' testimonies and past experiences.

TOP TIP: Health care professionals have an ethical obligation to protect their patients' privacy, but won't mind you asking about how you might get in touch with others in a similar position to you. They will be able to inform you on how to get in touch with support groups or other patients who are interested in talking to others.



The Internet

Here are some of the ways you might use the Internet to connect with others.

Blogs

A blog is an online journal in which the writer or blogger can reflect, share opinions, and discuss various topics. You can find examples of cancer blogs through:

- Canadian Cancer Society, www.cancer.ca
- Blog for a Cure, www.blogforacure.com
- Young Adult Cancer Canada, www.youngadultcancer.ca/links/
- Finding Hope (Canadian Breast Cancer Foundation), <http://findinghope.cbcf.org>

Online Forums

These are like message boards or bulletin boards. You can read other people's comments and can also contribute your own comments on a particular topic. For example, see:

- Canadian Cancer Society, www.cancerconnection.ca
- Cancer Compass (US), www.cancercompass.com
- I Had Cancer, www.ihadcancer.com

Chat Rooms

These allow you to connect with other people about particular topics by emailing questions having live chats with other people. Chat rooms are sometimes coordinated by a moderator. You can find chat rooms on specific cancers through sites such as:

- Cancer Chat Canada, www.cancerchatcanada.ca
- American Cancer Society Cancer Survivor Network, www.csn.cancer.org
- National Cancer Institute, <https://www.cancer.gov>

Social Networks

These are websites that encourage connections between people with similar interests. Some cancer websites have social networks that you can join. Twitter and Facebook are other social networking tools that allow you to share short comments and personal updates via the Internet and your mobile phone. Many use these online platforms to promote, engage, and educate. For examples, see Canadian Cancer Society Facebook: www.facebook.com/CanadianCancerSociety and Twitter: www.twitter.com/cancersociety or @cancersociety

TOP TIP: Any information that you relay on social network sites and forums will be in the public domain. Consider your privacy before disclosing information.



What others say about using these strategies

“I was originally worried that the support group would be a big sob-fest of people feeling sorry for themselves. But it turned out to be the opposite. While most people were pretty realistic about things, they tended to do it in a constructive way – where you could learn something from what they had been through.”

Maria, partner of Rex, diagnosed with prostate cancer.

Key Points: Seeking emotional support from others

1. Many people with cancer and their partners find it helpful to share ideas and thoughts with people who understand what they are going through.
2. Health care professionals and others with similar experiences are useful sources of emotional support.
3. Contact with others may take the form of formal meetings (e.g. support groups) or informal connections (e.g. via Internet forums).

