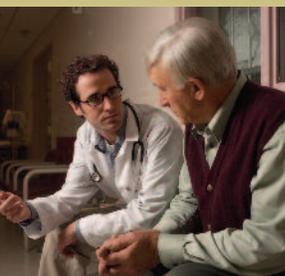


The “How To” Health Guide

2011



Disclaimer - The information on the Health Charities Coalition of Canada website is not meant to replace any medical advice provided by your health care team and is strictly a guide to steps that may be taken. If you suspect that you have a medical condition, consult your physician or medical advisor.

Health Charities Coalition of Canada (HCCC)

41 Empress Avenue, Annex D

Ottawa, ON K1R 7E9

www.healthcharities.ca



THE “HOW TO” HEALTH GUIDE

If you, or someone you love and care for, are trying to find health services, support or information for an illness or disease, there are actions you can take to help get the best possible health care.

This section of our website is a guide to help you learn how to:

- **Understand** the health care system
- **Find** the information and services you need
- **Review and Evaluate** the information you find
- **Talk** with your doctor or health care provider
- **Ask** for a second opinion
- **Manage** your condition
- **Pay** for your medication
- **Participate** in a clinical trial
- **Advocate** and ask for the support you need

Please note that the information on this website is not meant to replace any medical advice provided by your health care team and is strictly a guide to assist you during what can be a challenging journey.

HOW TO UNDERSTAND THE HEALTH CARE SYSTEM

Canada has a publicly funded health care system known as “Medicare.” Medicare provides free, medically necessary services such as care in a hospital or an appointment with a physician. To understand the health care system you need to learn how the federal government, provincial and territorial governments and, in some cases, health regions, are involved in the delivery of health care.

The **federal government** is involved in the health care system in a number of ways including:

- Determining national principles for the health care system. For more details, see our information on the [Canada Health Act](#).
- Providing financial support to the provinces and territories
- Directing delivery of health care services to:
 - First Nations people living on reserves
 - Inuit
 - the Canadian Forces
 - the Royal Canadian Mounted Police
 - eligible veterans
 - inmates in federal penitentiaries
 - refugee claimants

For more information, see our section on the [Federal Government and Health Care](#).

The **provincial and territorial governments** plan for and provide Medicare free of charge. (Medicare covered health services are funded through taxes). Most provinces and territories also provide additional services for certain groups such as low-income residents and seniors such as:

- drugs prescribed outside hospitals
- ambulance costs
- hearing, vision and dental care not already covered

Most provinces and territories have health regions to administer public health care services to Canadians. Health regions are also referred to as regional health authorities, Local Health Integration Networks (LHINs) or health agencies. Many provinces and territories also have telephone health information lines. To see this information go to our section on [Call-In Health Lines](#).

In addition, each province and territory has a **workers’ compensation** agency, funded by employers, which provides services to workers who are injured on the job.

For more information, see our section on the [Provincial and Territorial Governments and Health Care](#).

HOW TO FIND THE INFORMATION AND SERVICES YOU NEED

One of the first steps is to learn all that you can about your disease or condition and the treatments available. Being knowledgeable can have a direct affect on your overall well-being by helping you to make informed decisions about your health care.

There are many sources of health-related information. Some of the most reliable sources include:

- Your family doctor
- Your local hospital
- The Internet
- The Public Library
- Other health professionals such as your pharmacist, physiotherapist, psychologist, occupational therapist, social worker or other specialists
- Community health service centres or clinics and public health professionals such as nurses, dieticians, and others
- Alternative medical practitioners such as chiropractor, naturopath, acupuncturist and others
- Check with your provincial or territorial Ministry of Health for the information and resources such as telephone health lines. For more information, see our section on the [Provincial and Territorial Governments and Health Care](#).

Health Charities

There are a number of health charities in Canada that provide support for patients as well as their caregivers. They do this by providing patient education programs, disease and treatment information, patient support groups, online discussion forums, various rehabilitation programs, patient self-help management programs and many other initiatives.

In many cases, health charities have physicians and other health care professionals that they work with who can help answer specific questions that you may have. For more information, see our list of members at the [Health Charities Coalition of Canada](#).

HOW TO REVIEW AND EVALUATE HEALTH INFORMATION ON THE INTERNET

The Internet is a good source of health-related information. However, since individuals, groups and organizations can easily create their own websites and

post any information they want, even if it’s not true, it’s important to make sure that you check the information and make sure that you can trust it. You should ask yourself some questions about the website before deciding to use the information you find on the internet. You can print out this checklist to help you do this.

- Who supports the website? Who maintains it? Who pays for it?
- How current is the information? Does the site post the date and when it was last updated?
- If the information on the site is not original, does the site provide references about the source of the information?
- Does the site display the name/logo of the institution or organization responsible for the information?
- Does the site display the author’s name, qualifications and credentials if relevant?
- What do other associations think of the site? Does it meet their approval?
- What is the purpose of the site? Is it to give you information or to sell you a product? Is the site a vehicle for advertising?
- Does the site post a disclaimer describing the limitations, purpose, scope and authority of the information?
- Is the information balanced or more one-sided?
- Does the site post links to other appropriate sites so you can read more?
- Is the site well designed so you can navigate it easily?
- Is there a way to send comments and feedback on the site?

To learn more about how to review and evaluate health information on the Internet go to the [Dalhousie University Library](#) site.

HOW TO TALK WITH YOUR DOCTOR OR HEALTH CARE PROVIDER

Patient Rights and Responsibilities

As a Canadian patient, you have rights. You have the right to treatment, a right not to be refused urgent care, a right to a diagnosis, a right to coverage, and even a right to appeal if other rights have not been respected.

You also have responsibilities such as providing accurate information to your health care team, asking questions to make sure you understand the information being shared with you and following your treatment plan. It is really important for you as a patient to take an active role in your health care. To make sure you get the answers you need about your disease or condition and treatment, educate yourself and learn to talk to your doctor and other members of your health care team.

Many patients feel anxious when they are first diagnosed and can be nervous when they talk to their family physician or specialist. This section provides information about questions to ask the doctor, tips on how to get all the information you need out of each appointment and how to ask for a second opinion.

What to say

Before you see the doctor, make a list of the following information. Start to make the list well in advance of your doctor’s appointment. If you try to remember all of this information the day before, you may forget some important points. Be sure to list:

All of your symptoms – for example, your experience with pain, sleeplessness, cough, headache, trouble breathing, anxiety, depression and others

- How long you have had each of the symptoms – for example, joint stiffness in the morning over the past 3 months
- How you feel during the course of a 24-hour period – for example, stiffness in the morning upon waking, nausea following meals, headache in the afternoon and throughout the evening and others
- List what you have tried already, what helps and what makes it worse
- List all the medications that you are currently taking, including prescription drugs, over-the-counter medications, herbal remedies, supplements and others

What to ask

During your appointment with the doctor or health care professional, get the answers to the following questions. Do not be afraid to take notes. We often forget what we are told during our appointments with physicians. You may wish to bring a family member or friend along to medical visits to make sure you don’t miss important information. As a courtesy, tell your doctor why you are taking notes. For example, the amount of information told to you can be overwhelming; therefore you would like to have a record of the information to refer to.

- What do you think is wrong with me? What is my diagnosis?
- Do I need to have test(s)? If so, when will I have the test(s)?
- What is the reason for the test(s)?
- When and how will I get the results from my tests?
- What are my treatment options?
- What are the next steps?
- Does the hospital, clinic, medical office, etc., have a social worker or patient advisor that can help me to better understand the next steps?
- Do you have any patient information sheets or brochures that I can read to educate myself?
- Where can I get more information about my condition?

- Is there a health charity or support group I can contact for my particular disease or condition?
- Are there any lifestyle changes that I need to make?
- What more can I do for myself to help improve my condition?
- Is there a self-management program that I should attend?
- Who should I contact/where should I go if I start to feel worse?

HOW TO ASK FOR A SECOND OPINION

Do not be afraid to seek a second opinion about your health. It is your right as a patient and a second opinion may help you to learn more about your disease, gain a different perspective on treatment options, and reassurance and peace of mind that you are making the right treatment decisions.

- Many patients worry about telling their doctor they plan on seeking a second opinion, but they shouldn't. Most doctors are comfortable with the request, particularly in the case of a serious disease diagnosis.
- If you have been diagnosed with a serious illness and would like a second opinion but are nervous about offending your specialist, ask your family physician to make the referral to a second specialist.

HOW TO MANAGE YOUR CONDITION

Patients with chronic and even terminal conditions can contribute to their own care through patient self-management programs. Self-management programs help you, as well as your caregiver, to better understand your disease or condition, teach you to cope with your symptoms and show you how to be more involved in managing your disease and care.

Self-management programs usually include information about:

- Managing physical symptoms to reduce their negative impact on daily living, e.g., pain, stiffness, bowel and bladder issues, etc.;
- Exercise;
- Nutrition;
- Avoiding tobacco use;
- Taking medications properly;
- Dealing with stress and depression;
- Working with your doctor and health care team to make the best treatment and care choices for you;
- Evaluating alternative treatments; and
- Planning ahead with your family and health care team to obtain appropriate assistive technology if necessary to help with activities of daily living.

The benefits of self-management programs could include fewer trips to the doctor, better control over your disease or condition and possibly improved overall wellness. Even if your condition is certain to worsen over time and may be life limiting, managing symptoms and making timely decisions about care and support can prevent unnecessary injuries, infections, fatigue, and may increase survival time and quality of life.

Ask your doctor, health care professional or health charity representative if there is a self-management program or resource material available for you.

HOW TO PAY FOR YOUR MEDICATION

(Adapted with permission from the Myeloma Canada website)

Not all medications that have been approved by Health Canada are covered by publicly funded drug plans or private insurance plans. Do your research to make sure you know what is covered by your specific plan and how much you will have to pay.

Publicly Funded Drug Plans

- Each province has different rules for their **publicly funded drug plans**. For example, some provide coverage for individuals 65 and older or individuals on social assistance. Some provinces provide special support for individuals who face substantial drug costs compared to their income. Talk to your doctor and other members of your health team.
- You should also call your **Provincial Ministry or Department of Health** to get more information about the terms of the various publicly funded drug plans.
- Even if you are eligible for coverage under one of the public plans, you may still have to pay some amount in the form of either:
 - a co-payment (a flat fee that you pay with each prescription);
 - a co-insurance (a percentage that you pay with each prescription);
 - a deductible (a certain amount that you pay with each prescription until you reach a maximum amount, at which time the public plan pays 100% of the prescription); and
 - a premium (a payment that you make whether you receive a prescription or not).

Quebec Public Drug Program

- In Quebec, unlike any other province or territory, everyone must be covered by prescription drug insurance. There are two types of plans, private plans and the public plan, which is administered by the Régie l'assurance maladie du Quebec (RAMQ). Private plans are group insurance or employee benefit plans. See private drug plans for more information.

- The Public Prescription Drug Insurance Plan in Quebec is intended for: individuals 65 and over; recipients of financial assistance; individuals not eligible for a private plan; and children of those covered by the public plan.
- Generally speaking, individuals covered by the public plan must pay a premium, whether or not they purchase prescription drugs. The premium is collected when income taxes are filed.

For more information, visit the [Quebec Prescription Drug Insurance](#) website.

Private Health Insurance or Drug Plans

- If you have **private health insurance** or a **drug plan** at work, take the time to study your plan and know your benefits.
- If you are employed, meet with your human resources department or union representative to help you better understand your benefits.
- Ask your doctor what medications you may need in the future, and check to see if your plan covers them.
- If you are covered by more than one plan, try to coordinate your benefits so any portion of a drug cost that is not paid for by one plan is applied to the next.
- Your private insurance plan may require that you **pay for your medications upfront** to the pharmacist and then submit the receipts for reimbursement. If this is a problem for you, ask your insurance company to allow your pharmacy to submit the bill directly to them for reimbursement.
- **If the medication you require is not covered** by your health insurance plan, do not be afraid to speak to a human resources manager, union representative or employer and ask if they can make an exception. If you are refused coverage for a medication you need, call the insurance company to ask why or make an appeal. In some cases, the refusal may be the result of faulty paperwork. Sometimes, the company will change its mind as a result of your appeal.

Pharmaceutical Companies

- Some pharmaceutical companies have free services that will **help you search** for coverage of specific drugs or even supply you with the drug you require. Talk to your doctor or medical care team or search online to see if you may be eligible for such a program.
- Some pharmaceutical companies provide drugs or medical supplies to patients who cannot afford them or who do not have government or private insurance, under their **Compassionate Use Programs**. Each company program has its own terms for eligibility. These Compassionate Use Programs should not be considered as a replacement for public or private insurance coverage, and certainly are unable to meet the need for medications and supplies across Canada.

Catastrophic Drug Coverage

Most provinces and territories provide coverage for residents who spend a large part of their income on prescription medications or for certain high-cost drugs. These programs are not meant to replace private insurance plans or publicly funded drug plans. Contact your **ministry or department of health** to find out if there is a plan available for you.

For more information on **prescription drug reimbursement** in Canada go to the [Drug Coverage Guide to Reimbursement](#) website.

If you are interested in learning more about how drugs are reviewed and approved in Canada, see our section on [The Drug Approval Process](#).

HOW TO PARTICIPATE IN A CLINICAL TRIAL

(adapted with permission from the Amyotrophic Lateral Sclerosis Society of Canada (ALS) information on “Clinical Trials – A Primer”)

Drugs are tested in a number of different ways before they are submitted to Health Canada for approval. One of these ways is through clinical trials. A clinical trial is a research study which uses volunteers to determine whether or not a new treatment, drug or device is effective and safe.

It can take up to five years, or even longer in some instances, to ensure that newly developed treatments are safe for research with human participants. Each clinical trial has a set of rules (protocols) for the research which will outline eligibility criteria for participants (age, gender, medical history, etc.), the number of participants they need, how long the trial will last, treatment details and information about some of the potential side-effects. For more information about the development of clinical trials, see our section on [Clinical Trial Phases](#).

You may be interested in participating in a clinical trial because it makes a valuable contribution to research and can give you access to new treatment before it becomes widely available. There are some risks such as unknown side-effects and/or there may be additional costs involved in participating in a clinical trial (e.g. more frequent travel to the study site). If you are interested in participating in a clinical trial you should talk to your doctor and make sure you understand all of the facts (informed consent) before making your decision.

Questions to ask your doctor if you are considering participating in a trial

- What is the purpose of the study?
- How does it support progress toward a better treatment and cure?
- Who has reviewed and approved the study?

- What are the risks? What are the benefits?
- How does this treatment compare with other treatments available?
- What kinds of tests and procedures will be required? Where will they take place?
- How long will I receive the treatment?
- Will the study require extra time, effort or expenses on my part?
- What does my family need to know?
- Where can I learn more about the study and the researchers involved?

Health charities are often a valuable source of information about various clinical trials for specific treatments available in Canada or the United States. For more information, see our list of members at the [Health Charities Coalition of Canada](#). Other sources of information include the [Canada Trials](#) website, the [Canadian Cancer Trials](#) website and the [National Cancer Institute](#) website.

HOW TO ADVOCATE FOR [GET] THE SUPPORT YOU NEED

If you, or someone you love or care for, are not receiving the care you need from your health care system, there are steps you can take to help make changes. Speaking out to make a change is referred to as advocacy. Successful advocacy is based on your ability to identify and explain your issue and propose an effective solution.

1. What is your issue? What do you want to see changed? Why does it concern you?
2. Who do you need to talk to? Who has the authority to make the change? (the hospital? The Minister of Health? Your insurance company?)
3. How will you explain your issue? What can you do to deliver your message? (a letter? A meeting? Both?)
4. When asking for a change, keep your request or “ask” to just one. This will help you to focus on the thing that you need the most and not a list of things that you would like to have.

Be sure to contact the health charity/organization associated with your condition to see if they are already advocating for the same issue(s) you are.

TELL YOUR PERSONAL STORY TO HELP CREATE CHANGE

Telling your personal story is a very powerful and effective way to help create change. Whether you are speaking to a politician, government official, other advocates or the media, your personal story helps to bring the issue to life and

adds importance to the solution. Your personal story allows you to connect in a meaningful way with those in a position to make decisions for change.

There are things you should keep in mind when you are preparing to tell your story to help get the message across:

- Be clear: what is the issue? How has it affected you? What do you want to change?
- Be brief: you should take no more than 5 minutes to tell your story
- Be personal: share your experiences, feelings and observations about how this has effected your life

Share your story

In order to show others how patient advocacy works, we kindly ask you to share your story. If you have been successful in creating change to improve the health care system, please share your story with us by sending an e-mail message no longer than 200 words to the [Health Charities Coalition of Canada](#). Please include your name and contact information so that we can reach you if needed. We will post your story on our website so that others may benefit from your experience. We will not post any personal information.

For more information on advocacy, see our section on [Advocacy Tools and Techniques](#).

BACKGROUND INFORMATION THE FEDERAL GOVERNMENT AND HEALTH CARE

In order to receive federal funding for health care, each provincial and territorial government must meet five criteria as stated in the federal government’s *Canada Health Act*.

Description of the **five criteria** for delivering health care:

- Public Administration – must be administered and operated on a non-profit basis by a public authority that answers to the provincial or territorial government.
- Comprehensiveness – must insure all medically necessary services provided by hospitals, medical practitioners and dentists working within a hospital setting.
- Universality – must entitle all insured persons to health insurance coverage on uniform terms and conditions.
- Accessibility – must provide all insured persons reasonable access to medically necessary hospital and physician services without financial or other barriers.

- Portability – must cover all insured persons when they move to another province or territory within Canada and when they travel abroad.

Note: The provinces and territories have **some limits** on coverage for services provided outside Canada, and may require prior approval for non-emergency services delivered outside their jurisdiction.

In addition to providing funds to support health care delivery in the provinces and territories and direct delivery of care to certain groups, the federal government also provides:

- Public health programs to **prevent disease**, and to promote health and educate the public on health implications of the choices they make;
- **Health protection** that includes food safety and nutrition, and regulation of pharmaceuticals, medical devices, consumer products and pest management products;
- Funding for **health research** and health information activities; and
- Federal health-related **tax measures** that include tax credits for medical expenses, disability, caregivers and infirm dependents, tax rebates to public institutions for health services, and deductions for private health insurance premiums for the self-employed.

For more information about the role of the federal government in health care go the [Health Canada](#) website or the [Public Health Agency of Canada](#) website.

THE PROVINCIAL AND TERRITORIAL GOVERNMENTS AND HEALTH CARE

Provincial and territorial health care includes care in a hospital and the services of a physician or other health professional (medicare). Provincial and territorial governments:

- Administer their health insurance plans
- Plan, pay for and evaluate hospital care, physician care, allied health care, prescription drug care in hospitals and public health; and,
- Negotiate fee schedules for health professionals.

For more information about the role of the provincial and territorial governments in health care go the [Health Canada](#) website or follow one of links below to learn more about the specific services in your area:

Provincial and Territorial Ministries of Health

British Columbia	Ministry of Health Services	www.gov.bc.ca/health
Alberta	Alberta Health Services	www.albertahealthservices.ca
Saskatchewan	Ministry of Health	www.health.gov.sk.ca
Manitoba	Manitoba Health	www.gov.mb.ca/health
Ontario	Ministry of Health and Long-Term Care	www.health.gov.on.ca
Quebec	Ministry of Health and Social Services	www.msss.gouv.qc.ca
New Brunswick	New Brunswick Health	www.gnb.ca
Nova Scotia	Department of Health	www.gov.ns.ca/health
PEI	Department of Health and Wellness	www.gov.pe.ca/health
Newfoundland and Labrador	Department of Health and Community Services	www.health.gov.nl.ca/health
Yukon	The Department of Health and Social Services	www.hss.gov.yk.ca
Nunavut	The Department of Health and Social Services	www.gov.nu.ca/health
Northwest Territories	Department of Health and Social Services	www.hlthss.gov.nt.ca

Provincial and Territorial Regional Health Authorities and Organizations

British Columbia	British Columbia Health Authorities	www.health.gov.bc.ca/socsec/contacts.html
Alberta	Community Health Services-Inform Alberta	www.albertahealthservice.ca
Saskatchewan	Regional Health Authorities	www.health.gov.sk.ca/health-region-list
Manitoba	Community Health Centres	www.gov.mb.ca/health/guide/4.html
Ontario	Community Care Access Centres	www.ccac-ont.ca
Quebec	Centre local de services communautaires-local community service centre	www.indexsante.ca/CLSC
New Brunswick	NB Social Development	www.gnb.ca/0017/Index-e.asp
Nova Scotia	Community Health Boards	www.communityhealthboards.ns.ca
PEI	Department of Health and Wellness	www.gov.pe.ca/health
Newfoundland and Labrador	Department of Health and Community Services	www.health.gov.nl.ca/health
Yukon	The Department of Health and Social Services	www.hss.gov.yk.ca
Nunavut	The Department of health and Social Services	www.gov.nu.ca/health
Northwest Territories	Department of Health and Social Services	www.hlthss.gov.nt.ca

Provincial and Territorial Call-in Health Lines

British Columbia	BC Nurseline	8-1-1
Alberta	HealthLink Alberta	1-866-408-5465
Saskatchewan	Saskatchewan HealthLine	1-877-800-0002
Manitoba	Manitoba Health Links	1-888-315-9257
Ontario	Telehealth Ontario	1-866-797-0000
Quebec	Info-Sante	8-1-1
New Brunswick	Tele-Care New Brunswick	1-800-244-8353
Nova Scotia	HealthLink	8-1-1
Newfoundland and Labrador	Newfoundland and Labrador HealthLine	1-888-709-2929
Yukon	Yukon HealthLine	8-1-1
Northwest Territories	NWT Health Line	1-888-255-1010

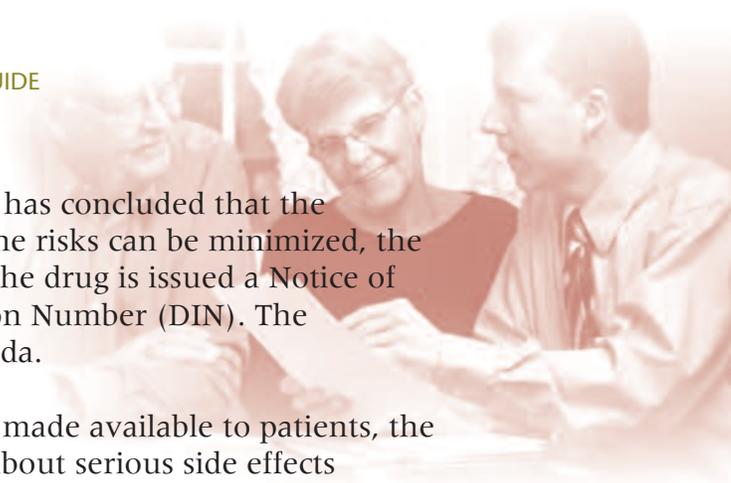
THE DRUG APPROVAL PROCESS IN CANADA

In order for a drug to be available for sale in Canada, it must go through the drug review process. The process starts when a manufacturer of the drug submits an application known as a “New Drug Submission” to Health Canada.

The New Drug Submission contains information and data about the drug’s safety, usefulness and quality. The submission also includes the results of preclinical and clinical studies, details about the production of the drug, packaging and labeling details, and information regarding the beneficial claims and side effects.

Scientists in the Therapeutic Products Directorate (TPD) of Health Canada, and sometimes, outside experts, review the safety, effectiveness and quality of the data provided in the submission, and they evaluate the potential benefits and risks of the drug.

The TPD also reviews the information that the manufacturer intends to provide to doctors and other health care practitioners and consumers about the drug. This includes the information that will appear on the drug label and related brochures.



Once the review process is complete and the TPD has concluded that the benefits of the drug outweigh the risks and that the risks can be minimized, the drug is approved. With Health Canada approval, the drug is issued a Notice of Compliance (NOC), as well as a Drug Identification Number (DIN). The manufacturer is now able to sell the drug in Canada.

Once a new drug has been approved and is being made available to patients, the manufacturer must report any new information about serious side effects including the drug’s failure to provide its health benefit. The manufacturer must also notify the TPD about any studies that have provided new safety information.

The TPD monitors adverse events, investigates complaints and problem reports, maintains post-approval observation, and manages recalls of the drug, should that be necessary. In addition to monitoring the drugs once they are available for use in Canadian patients, the TPD licenses most drug production sites and conducts regular inspections as a condition for licensing.

Special Access Program

In some cases, physicians may be able to prescribe a drug, which is not currently available in Canada through the Special Access Program. This is done in rare cases when it is the physician’s belief that other therapies have failed or are not appropriate. The drug is only released after the TPD has determined that the need is justifiable and that a qualified physician is involved.

Common Drug Review

Once a drug has been approved for sale by Health Canada, the manufacturer must submit an application to the Common Drug Review if they wish to have their drug listed on publicly funded drug plans. All provinces and territories, with the exception of Quebec, participate in the Common Drug Review (CDR). CDR is part of the Canadian Agency for Drugs and Technology in Health (CADTH).

The CDR is a single, national process that reviews and makes recommendations as to whether new drugs should be covered under public drug plans. The CDR was developed to help address increasing public spending on drugs. It operates under the principle that new drugs should be added to a formulary only after an assessment of their cost-effectiveness.

Once a recommendation is made, the drug plan decides whether or not to include the drug on the formulary (drugs that are covered by the plan). The drug plans are not required to follow the recommendation because each plan must also consider its own health care priorities and available resources. For more information, visit the [Common Drug Review](#) website.

CLINICAL TRIAL PHASES

Clinical trials are used to measure whether a drug is safe in humans, can prevent or treat disease, how well it works, and its usefulness for other conditions. The different types of clinical trials include disease treatment, prevention and screening, as well as quality of life.

The first level of testing is known as pre-clinical. This level of testing occurs before the substance can be tested on humans to see how it actually works. The substance is tested in a lab in tissue cultures and a variety of small animals to see if any significant changes occur. It is at this stage that the product strength and dosages are determined. Clinical trials then take place in four phases and each phase uses more people. The clinical trial process is very complex and can take many years to complete. A very simple description is as follows:

- Phase I – 20 to 100 healthy volunteers are used to see how they respond and tolerate different doses of the substance.
- Phase II – 100 – 300 patients with the disease are used to measure short-term side effects and more appropriate dosages.
- Phase III – 1,000 to 3,000 patients with the disease are used to confirm the usefulness and further test side effects. In this phase the final dosage is set for different types of patients.
- Phase IV - all studies conducted after the drug has been approved for sale by Health Canada. These tests are done to ensure the most effective use of the drug and to further support its usefulness.

If you are interested in knowing about clinical trials that are currently underway, you can access information on these websites:

<http://www.clinicaltrials.gov/ct2/info/about>

<http://clinicaltrials.ifpma.org/clinicaltrials/en/myportal/index.htm>

ADVOCACY TOOLS AND TECHNIQUES

There are different kinds of advocacy, personal and issued based. Personal advocacy is when you are speaking up about an issue that has a specific effect on you, a family member, a friend or a loved one.

Issue-based advocacy is when you are speaking up about an issue on behalf of a large group of affected people. This way, you not only help yourself, but also help others who may not be able to help themselves. When you speak up for yourself, or an affected group, as a patient, we call that patient advocacy.

Please note that some times you may not be speaking up to make a change, but to prevent a change that may have a negative affect on you and others. This type of action is also included in advocacy.

Advocacy can lead to meaningful change. People in a position of authority, who have the power to make changes (politicians, government officials, hospital administrators, etc.), respond to individuals and groups who are able to clearly communicate their concern and propose an effective solution.

- Identify and explain your issue;
- Understand and explain your issue better than anyone in government;
- Fit your issue within an existing government agenda or use it to set a new agenda; and
- Build on existing relationships with decision makers or create new relationships.

In order to establish your credibility, you need to show that you know your issue really well. And, that you know all the facts that support your concern and proposed solution. There are three basic steps to creating an effective advocacy plan:

1. Develop your key messages
2. Create your advocacy tools
3. Focus on one main request – your one “ask”

Step 1 – Develop your key messages

Politicians and other decision makers that you are trying to influence hear many different messages from many different people and groups all the time. If you want them to hear you, make sure your message stands out and that you deliver it to the right person at the right time.

1. What - Identify your issue
 - Focus on the things that you are concerned about and want to see changed.
 - Take a position or stand.
 - If you are working with a group, make sure everyone agrees with the issues and the positions taken.
2. Why - Explain the issue
 - Write out three key messages that explain your issue and your concerns in clear language.
 - Your key messages must be brief, easy to remember, simple, true and provable.
 - Practice presenting your key messages to family and friends who may not be aware of your issue to see if they are able to understand your concern.
 - Rehearse your key messages, as they will form the basis for all written and verbal communication with decision-makers, other advocates and the media.

3. Who - Deliver your message to the right people
 - Your issue will determine what level of government has the authority to make a change. It will be either the federal, provincial/territorial, or local government.
 - Once you have identified the level of government responsible, contact your local representative - either your federal Member of Parliament (MP), or your Member of Provincial Parliament (MPP) (known in some provinces as a Member of the Legislative Assembly (MLA), or Member of the National Assembly (MNA) or Member of the House of Assembly (MHA)) or your municipal councilor as a starting point.
 - Your provincial or territorial government deals with most health care issues. You can find your provincial representative by searching on the homepage of your provincial or territorial government website or the blue pages of your telephone directory.
 - In addition to elected representatives, there are government staff people who work on health policy matters. They should be contacted as well.
 - Develop a contact plan of all the individuals you need to contact regarding your issue of concern and your three key messages.

4. When – Deliver your message at the right time
 - A prime time to deliver your key messages is when the issue appears in the media and public awareness is high and in your favour.
 - Another important opportunity is when a newly elected politician takes office; he or she may be looking for a new issue to help support.
 - An election is also a good time to share your concerns. Make sure you approach all of your local candidates with your issues to see where they stand.

Step 2 – Advocacy Tools

There are a number of tools that can be used to deliver your message to decision-makers. Some include: in-person meeting, telephone call, letters/faxes/e-mails, newsletters, brochures, postcard campaign, petition, website, information sessions, Advocacy Day, fact sheet, social media, etc.

Advocacy is a process. There are three components that must follow, regardless of the communication tool being utilized:

Educate – use your key messages, your personal story and other key facts to educate the people that can make the changes you request.

Demonstrate – show how your issue matters not only to you, the group you represent, but also to the person you are trying to influence.

Advocate – once you have educated and demonstrated it is time to make your request. Ask for the change you are seeking.

A description of some advocacy tools:

Letter to your elected representative asking for a meeting

Sample outline of a letter:

- First paragraph – who you are (always note that you are a constituent) and why you are writing to your elected representative (your 'ask')
- Second paragraph – a brief paragraph outlining your personal story and your link to the issue
- Third paragraph – a combination of your three key messages and some key facts about the issue
- Fourth paragraph – restatement of your 'ask' (in bold)
- Fifth paragraph – *I will be in touch shortly to arrange a time to meet* – thank-you

In-Person meeting script:

For use when meeting with an elected representative or other government official.

- Introduce yourself and the people you are with
- Explain why you are there and your one 'ask'
- Deliver your three key messages
- Tell your personal story as it relates to the issue
- Review some of your key facts
- Deliver your one 'ask' again
- Engage in dialogue to ensure that your elected representative fulfills your one 'ask'
- Conclude by saying thank you and commit to following up shortly

Fact Sheet:

- No longer than one page
- To be as background information about the issue and in your meeting with your elected representative
- It is not necessary to deliver every key fact in your meeting
- In some cases, the Fact Sheet could be used as a leave-behind with the elected representative
- List province-specific information if available, as opposed to just national facts/figures

Letter to the Minister of Health:

Some issues are significant enough to write directly to the Minister in addition to your elected representative.

- First paragraph – who you are (always note that you are a constituent) and why you are writing to your elected representative (your ‘ask’)
- Second paragraph – a brief paragraph outlining your personal story and your link to the issue
- Third paragraph – a combination of your three key messages and some key facts about the issue
- Fourth paragraph – restatement of your ‘ask’ (in bold)
- Fifth paragraph – *I will be in touch shortly to arrange a time to meet – thank-you*

Step 3 – Your one “Ask”

When it comes to making your request to a decision-maker, keep your request or “ask” to just one. This will urge you to focus on the thing that you need the most and not a list of things that you would like to have. If you are working on behalf of a group, selecting one ask will strengthen the consensus and support from the individual members of the group.

APPENDIX

Recognition of Sponsor

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Members of HCCC’s Standing Committee on Health Policy:

Sharon Baxter, Chair

Executive Director, Canadian Hospice Palliative Care Association

Aaron Levo

Assistant Director, National Public Issues, Canadian Cancer Society

Jane McCarthy

Director of Services & Education, ALS Society of Canada

Lynn Moore

Director, Public Affairs, The Arthritis Society

Mary Pat Shaw

Vice-President, National Programs & Operations, Canadian Lung Association

Nadine Valk

National Director, Programs and Public Policy, The Kidney Foundation of Canada

Deirdre Freiheit

Executive Director, Health Charities Coalition of Canada