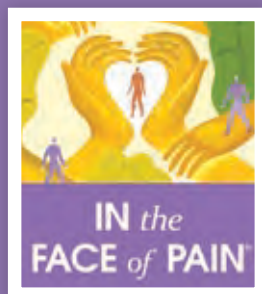




the handbook

for people with **pain**

a resource guide
5th edition



Dear Member of the Pain Advocacy Community,

We are pleased to bring you the newly-updated In the Face of Pain® **“Handbook for People with Pain,”** now in its 5th edition. Our goal is to provide a practical and actionable resource to help you, your loved ones, and your health care team address your pain. This Handbook will provide you with a variety of resources that we encourage you to use and share with others.

In 2011, the Institute of Medicine published the groundbreaking “Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research.” For the first time, a major institution quantified pain in terms of prevalence – more than 100 million Americans – and financial cost – more than \$560 million. While these impossibly large numbers are discouraging, the report also provided hope and encouragement through a series of recommendations to transform the way that pain is viewed in America.

We think that one of the most important recommendations is to “Promote and Enable Self-Management of Pain.” From our years of experience working with the pain community, we know that YOU are your best advocate when it comes to pain care. Working with your health care team to adequately assess your pain levels, taking a proactive role in making healthy choices and speaking up when it comes to your health care benefits are all ways that you can make a difference.

We would like to acknowledge the many organizations who generously allowed us to share their resources with you, and we hope that “The Handbook for People with Pain” will serve as a solid starting point in your journey toward self-advocacy.

You can download, share and order free copies of the Handbook at our In the Face of Pain website, www.IntheFaceofPain.com, where you can also find a wealth of information, tools and inspiration to keep you motivated.

Yours in Health,

The Purdue Patient and Professional Relations Team



Kimberley Tiller, RN, MPH
Associate Director

Craig R. Engesser, BSJ
Associate Director

Gina Barbarotto, MS, MBA
Associate Director

Pamela Bennett, RN, BSN, CCE
Executive Director



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Take an Active Role: Focus on Your Pain Care

You are the Expert on Your Pain!

You are a partner and the key source of information for your health care team, but identifying the right providers and communicating information can sometimes be a challenge.

The next few pages will provide information on:

- Communicating with your Health Care Team
- Pain Assessment Tools
- Medication Safety
- Healthy Lifestyle
- Resources and organizations that may be helpful in identifying members to add to your health care team

Communicating With Your Health Care Team

Asking questions and providing information to your doctor and other care providers can improve your care. Talking with your doctor builds trust and leads to better results, quality, safety, and satisfaction.¹

Quality health care is a team effort. You play an important role. One of the best ways to communicate with your doctor and health care team is by asking questions. Because time is limited during medical appointments, you will feel less rushed if you prepare your questions before your appointment.¹

Communication is a very broad term and includes both giving and receiving messages. When you are trying to give information to your health care providers remember to be:

- prepared
- concise
- considerate

The tools included on the following pages can help you be prepared with specific information that your health care providers can review and respond to. These are a great way to start a conversation and help you focus on the health goals that you would like to work toward.

Asking questions is important, but so is making sure you hear – and understand – the answers you get. Take notes. Or bring someone to your appointment to help you understand and remember what you heard. If you don't understand or are confused, ask your doctor to explain the answer again.²

Most of us think we are good listeners, but that's not always the case. Do you find yourself finishing others' sentences or formulating a response before the other person is finished speaking? If so, perhaps you're not listening as well as you think.

Active listening takes work but is invaluable in the communication process. Active listening is defined as: making a conscious effort to hear not only the words that another person is saying but, more importantly, trying to understand the complete message being sent.³ Do you actively listen to your health care team when they are reviewing treatment options and setting goals?



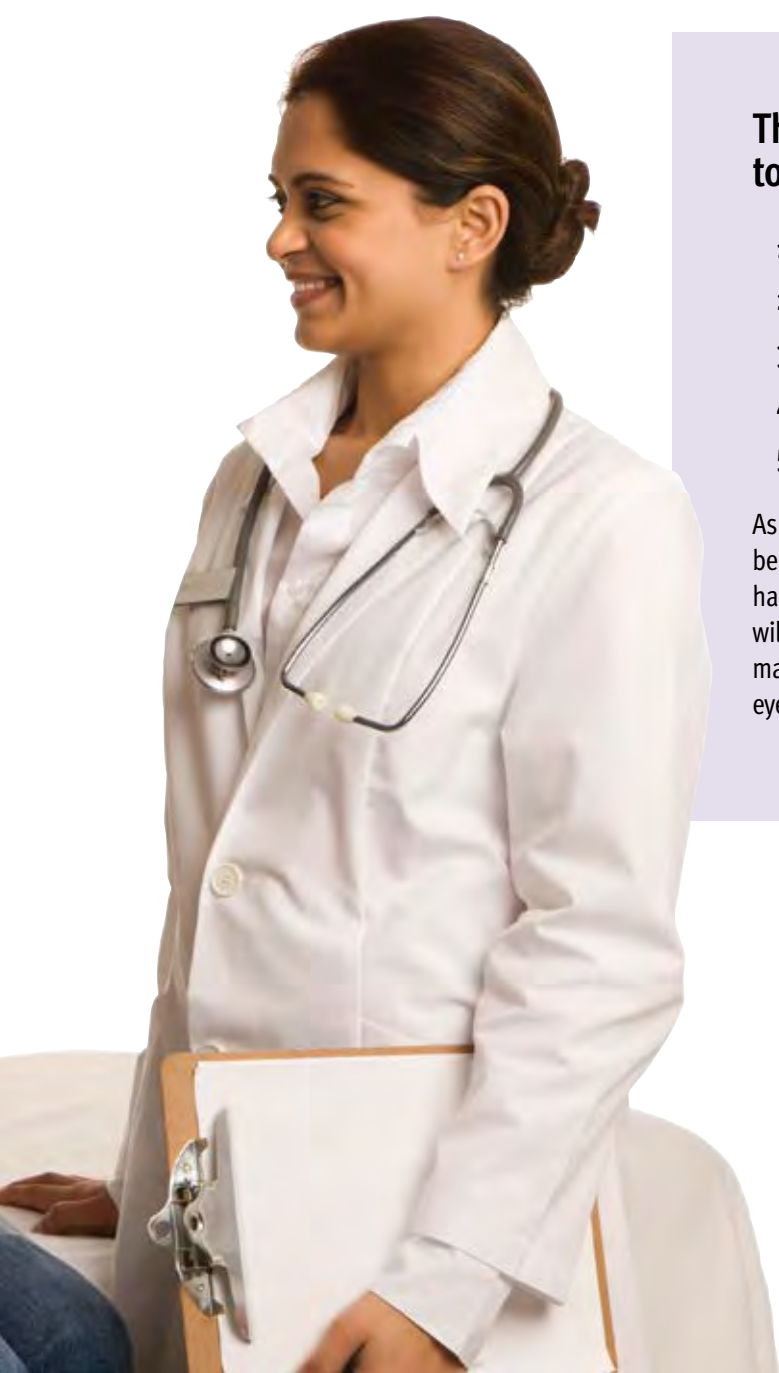
Be More Involved In Your Health Care:

Tips For Patients

This brochure from the Agency for Healthcare Research & Quality gives you tips to use before, during, and after your medical appointment to make sure you get the best possible care. One way you can make sure you get good quality health care is to be an active member of your health care team. Patients who talk with their doctors tend to be happier with their care and have better medical results.⁴

You can download a free copy of the brochure here:

www.ahrq.gov/consumer/beinvolved.pdf



The five key elements to active listening are:³

1. Pay attention
2. Show that you are listening
3. Provide feedback
4. Defer judgment
5. Respond appropriately

As with any other activity or skill, it can be improved but it takes practice. Perhaps if we practice our listening skills it will inspire others to follow suit, so let's make a special effort to listen with our eyes, ears and heart!

Sample Questions to Ask Your Health Care Team

Write down questions like these to bring to your next appointment.
Be sure to leave room for the answer!

1. What is causing my pain?
2. What can be done to make it better?
3. What can I do to help manage my pain?
4. What is my treatment plan?
5. What are the goals for my treatment plan? (See page 12 for an example)
6. Please tell me about the medications you prescribed for me:
 1. *What are the medications for and when do I take them?*
 2. *What effects should I expect?*
 3. *What should I do if I have side effects?*
 4. *Are there any risks associated with these medications?*
 5. *What if the medicine does not help?*
 6. *How should I store and dispose of unused medicine?*
 7. *How long will I be taking this medication?*
7. Are there alternatives to taking medicine?
8. What are the potential complications to those alternatives?
9. When will we evaluate the effectiveness of my treatment plan?

Health care providers know a lot about a lot of things, but they don't always know everything about you or what is best for you. Your questions give your health care provider and health care team important information about you, such as your most important health care concerns.¹

For examples of more questions go to the Agency for Healthcare Research and Quality (AHRQ): www.ahrq.gov/questionsaretheanswer



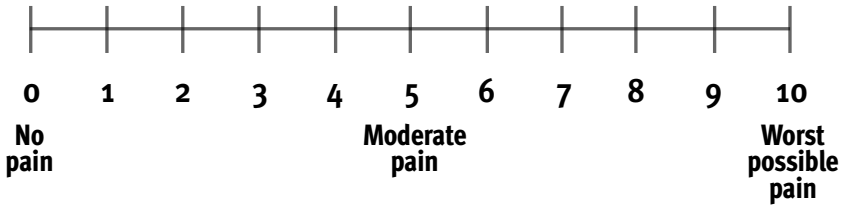
Pain Assessment Tools

The scales and tools on the following pages can help you take an active role in your pain care. By tracking the intensity of your pain, impact on various components of your life, time of day and circumstances, you will be better prepared to have a meaningful conversation with your provider. You may even begin to notice patterns that emerge surrounding pain levels at different times of day or after certain types of activity.



Patient Name: _____ Date: _____

0-10 Numeric Pain Intensity Scale*



* If used as a graphic rating scale, a 10-cm baseline is recommended.⁵

Patient Name: _____ Date: _____

Wong-Baker FACES™ Pain Rating Scale Instructions for Usage⁶

Explain to the person that each face is for a person who has no pain (hurt) or some, or a lot of pain.

Face 0 doesn't hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little bit more. Face 6 hurts even more. Face 8 hurts a whole lot. Face 10 hurts as much as you can imagine, although you don't have to be crying to have this worst pain.

Ask the person to choose the face that best describes how much pain he has.



0

No Hurt



2

Hurts Little Bit



4

Hurts Little More



6

Hurts Even More



8

Hurts Whole Lot



10

Hurts Worst

Live Better with Pain Log

Many things can affect your pain. These can include stress, sleep, money worries, and even the weather. When you and your doctor both understand what makes your pain worse, you can begin to work together on ways to reduce or deal with your pain “triggers.” This log is also available online at www.theacpa.org/painLog, where you have the opportunity to log in and record your pain levels, stress, activities and more on a daily basis.⁷

Live Better with Pain Log

Date _____

Name _____

Pain Level



No Pain

Worst Pain

1 2 3 4 5 6 7 8 9 10

Stress



No stress

Very Stressed

1 2 3 4 5 6 7 8 9 10

Exercise



Exercise daily

No exercise

1 2 3 4 5 6 7 8 9 10

Activity



Normally active

No activity

1 2 3 4 5 6 7 8 9 10

Sleep



Fully rested

Poor-quality sleep

1 2 3 4 5 6 7 8 9 10

Live Better with Pain Log *(continued)*

On these pages, mark the number that most closely matches your experience with each item over the last several weeks.

Fear of Pain



No Fear

Very Afraid

1 2 3 4 5 6 7 8 9 10

Using Medications as Prescribed



As Directed

Not As Directed

1 2 3 4 5 6 7 8 9 10

Side Effects



None

Strong Side Effects

1 2 3 4 5 6 7 8 9 10

Constipation



Normal

Irregular

1 2 3 4 5 6 7 8 9 10

Sexual Activity



Satisfied

Unsatisfied

1 2 3 4 5 6 7 8 9 10

Appetite



Normal appetite

1 2 3 4 5 6 7 8 9 10

No appetite

Mood



Cheerful & calm

1 2 3 4 5 6 7 8 9 10

Depressed, anxious

Interaction/isolation



Lots of interaction with family & friends

1 2 3 4 5 6 7 8 9 10

Always alone

Alcohol Use (drinks each day)



None

1 2 3 4 5 6 7 8 9 10

1 or 2

3 or 4

5 or 6

7 or more

Finances



No money worries

1 2 3 4 5 6 7 8 9 10

Serious money worries

Setting Goals

It's important that you and your health care team set mutually agreed upon goals for your pain management. These goals should be realistic and re-evaluated often.

Goals for management of your pain:

1. Improve function so that I can now _____
2. Pain decreased from (number) _____ to _____
3. _____
4. _____
5. _____

A comprehensive and individualized treatment plan may include many techniques. My treatment plan includes:

- | | |
|--|---|
| <input type="checkbox"/> Physical Modalities <ul style="list-style-type: none">• Physical Therapy (TENS, ultra sound, cold/heat)• Occupational Therapy (simplify activities of daily living, assistive devices)• Massage• Other | <input type="checkbox"/> Complementary & Alternative Medicine Approaches <ul style="list-style-type: none">• Yoga• Tai-chi• Acupuncture• Other |
| <input type="checkbox"/> Medication Management (see Medication pocket card) | <input type="checkbox"/> Nutrition <ul style="list-style-type: none">• ___ lb weight gain• ___ lb weight loss• Make healthier choices |
| <input type="checkbox"/> Psychosocial <ul style="list-style-type: none">• Biofeedback• Stress management• Support groups• Other | <input type="checkbox"/> Physical Activity <ul style="list-style-type: none">• ___ minutes of physical activity ___/week <input type="checkbox"/> Sleep Restoration <ul style="list-style-type: none">• ___ hours of sleep/night <input type="checkbox"/> Other |

Most of these components will be addressed later in this Handbook. You will also be provided with numerous websites where you can find more information on all of the above topics.

Personal Care Team Pocket Card

Fold Here if Desired

Patient Information

Name

Telephone Number(s)

Date of Birth

Allergies

Primary Care Professional

Name

Telephone Number(s)

Email

Fold Here if Desired

Pain Specialist

Name

Telephone Number(s)

Email

Pharmacy

Name

Telephone Number(s)

Email

Pharmacist

Name

Telephone Number(s)

Email

Fold Here if Desired

Nurse

Name

Telephone Number(s)

Email

Social Worker

Name

Telephone Number(s)

Email

Personal Care Team Pocket Card

Fold Here if Desired

Patient Information

Name

Telephone Number(s)

Date of Birth

Allergies

Primary Care Professional

Name

Telephone Number(s)

Email

Fold Here if Desired

Pain Specialist

Name

Telephone Number(s)

Email

Pharmacy

Name

Telephone Number(s)

Email

Pharmacist

Name

Telephone Number(s)

Email

Fold Here if Desired

Nurse

Name

Telephone Number(s)

Email

Social Worker

Name

Telephone Number(s)

Email

Message Therapist _____
Name

Telephone Number(s)

Email

Acupuncturist _____
Name

Telephone Number(s)

Email

— Fold Here if Desired —

Chiropractor _____
Name

Telephone Number(s)

Email

Fitness Center _____
Name

Telephone Number(s)

Email

Psychologist _____
Name

Telephone Number(s)

Email

— Fold Here if Desired —

Clergy _____
Name

Telephone Number(s)

Email

Other _____
Name

Telephone Number(s)

Email

— Fold Here if Desired —

Insurance Information

Name

Telephone Number(s)

Policy Number

Emergency Contact Information

Message Therapist _____
Name

Telephone Number(s)

Email

Acupuncturist _____
Name

Telephone Number(s)

Email

— Fold Here if Desired —

Chiropractor _____
Name

Telephone Number(s)

Email

Fitness Center _____
Name

Telephone Number(s)

Email

Psychologist _____
Name

Telephone Number(s)

Email

— Fold Here if Desired —

Clergy _____
Name

Telephone Number(s)

Email

Other _____
Name

Telephone Number(s)

Email

— Fold Here if Desired —

Insurance Information

Name

Telephone Number(s)

Policy Number

Emergency Contact Information

Medication Safety

Medicines play an important role in treating certain conditions and diseases, but they must be taken with care. By being an informed consumer and being involved in your health care, you can help decrease the risks and get the greatest benefit from your medicine.

You can do this by following the Food and Drug Administration's (FDA) recommendation to make medicine SAFER:⁸

- **S**peak up
- **A**sk questions
- **F**ind the facts
- **E**valuate your choices
- **R**ead the label and follow directions

The following pages cover topics that are important to medication safety, including medication adherence, safeguarding prescription medicines, prescription medicine misuse and abuse, and safe disposal of medication.



Medication Adherence

The quote by former U.S. Surgeon General, C. Everett Koop, “Drugs don’t work in patients that don’t take them,” sums it up nicely, but there are many reasons why people don’t always take their medication.

When you learn that you have a long-term health problem, one of the most important ways you can manage your condition is by taking your medicine as directed by your doctor, pharmacist, or other health care professional. This is also known as medication *adherence*.⁹



Fast Facts:⁹

More than one in three medicine-related hospitalizations happen because that person did not take their medicine as directed.

Almost 125,000 people die every year because they did not take their medicine as directed. It also costs the country nearly \$300 billion each year in additional costs for doctor visits, emergency room visits, hospital admissions and additional medicine.

The National Consumers League has developed a National Medication Adherence Campaign. For more information go to www.scriptyourfuture.org.

Safeguarding Prescription Medicines in Your Home: Your Personal Responsibility

When used as directed, prescription medicines can play a critical role in treating a range of debilitating diseases and conditions. Yet many don't realize the responsibilities that come with having prescription medicine – especially a controlled substance – in the home.

Unused and easily accessible medicines have the potential to be misused and abused, particularly by teens. According to the Substance Abuse and Mental Health Services Administration, the prescription medicines most commonly abused by teens aged 12-17 in 2013 include pain relievers, tranquilizers, stimulants and sedatives.¹⁰

Properly storing and disposing of prescription medicines in your home is an important way to reduce the risk of their misuse and abuse by family members and others.



Safeguard My Meds.

How to Store, Safeguard and Dispose of Prescription Medicine.

The Do's and Don'ts of Safe Medicine Storage¹¹

- 
- ✓ DO store medicines in a cool, dry place
 - ✓ DO ask your community pharmacist or other healthcare professional if the prescription medicine prescribed to you or a household member has abuse potential
 - ✓ DO lock up medicines that are at risk for being abused.
 - ✓ DO store medicines in original containers – the label on the bottle provides important information about the medicine such as who it is prescribed for and the date it was dispensed
 - ✓ DO keep track of how many pills you have during the course of treatment
 - ✓ DO discard medicines that are no longer needed or that have expired
 - ✗ DON'T leave medicines in places that are easily accessible for children or pets
 - ✗ DON'T share medicine with someone for whom it was not intended
 - ✗ DON'T repackage medicine in unmarked containers
 - ✗ DON'T leave medicines that are at risk for being abused in plain sight or in places that aren't secure
 - ✗ DON'T take medicines in front of children as they often mimic the behavior of adults
 - ✗ DON'T store medicine in a bathroom medicine cabinet where humidity and temperature changes can cause damage



The Reality of Prescription Medicine Misuse and Abuse

Prescription drug abuse, particularly among our nation's youth, is a major public health concern affecting families and communities. Consider the following recent data:

Among people aged 12 or older in 2012-2013 who used pain relievers nonmedically in the past year, 53.0% got the pain relievers they most recently used from a friend or relative for free. Another 10.6% bought them from a friend or relative. In addition, 4.0% of these nonmedical users took pain relievers from a friend or relative without asking.¹⁰

About one in five (21.2%) indicated that they got the drugs they most recently used through a prescription from one doctor. An annual average of 4.3% got pain relievers from a drug dealer or other stranger, 2.6% got pain relievers from more than one doctor, and 0.1% bought them on the Internet.¹⁰

The 2013 National Survey on Drug Use and Health found that an estimated 4.5 million persons aged 12 or older (1.7%) were current users of pain relievers.¹⁰

As with all medication, prescription pain medicine should only be taken by the person that it was prescribed to for the reason intended.

By being mindful of these stark realities and the potential for prescription drug abuse, you can take measures to help protect your medication from theft, and also your access to pain treatment. Prescription drug abuse is a serious issue that must continue to be addressed. At the same time, people who live with pain deserve access to timely and appropriate care.

Safe Disposal

What should you do with unused or expired medication? According to the Food and Drug Administration (FDA) almost all medicines can be thrown away in the household trash after mixing them with some unpalatable substance (e.g., coffee grounds) and sealing them in a container.

Certain medicines may be especially harmful if they are used by someone other than the person the medicine was prescribed for. It is for this reason that a few medicines have special disposal directions that indicate they should be flushed down the sink or toilet after the medicine is no longer needed.

A growing number of community-based “take-back” programs offer another safe disposal alternative. Proper disposal means they cannot be accidentally used by children, pets, or anybody else.

Additional tips from the FDA include:

- Before throwing out a medicine container, scratch out all identifying information on the prescription label to make it unreadable. This will help protect your identity and the privacy of your personal health information.
- Do not give medications to friends. Doctors prescribe drugs based on a person’s specific symptoms and medical history. A drug that works for you could be dangerous for someone else.
- When in doubt about proper disposal, talk to your pharmacist.

A complete tipsheet about safe disposal from the FDA can be downloaded here:¹²

www.fda.gov/downloads/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/UnderstandingOver-the-CounterMedicines/ucm107163.pdf

To learn more about drug disposal, visit the Drug Enforcement Administration’s website here:¹³

www.deadiversion.usdoj.gov/drug_disposal/index.html



Patient Information

Name

Telephone Number(s)

Date of Birth

Allergies

— Fold Here if Desired —

Health Care Professional

Name

Telephone Number(s)

Name

Telephone Number(s)

Name

Telephone Number(s)

— Fold Here if Desired —

Name

Telephone Number(s)

Name

Telephone Number(s)

Pharmacy

Name

Telephone Number(s)

— Fold Here if Desired —

Insurance Information

Name

Telephone Number(s)

Policy Number

Emergency Contact Information

Name

Telephone Number(s)

Patient Information

Name

Telephone Number(s)

Date of Birth

Allergies

— Fold Here if Desired —

Health Care Professional

Name

Telephone Number(s)

Name

Telephone Number(s)

Name

Telephone Number(s)

— Fold Here if Desired —

Name

Telephone Number(s)

Name

Telephone Number(s)

Pharmacy

Name

Telephone Number(s)

— Fold Here if Desired —

Insurance Information

Name

Telephone Number(s)

Policy Number

Emergency Contact Information

Name

Telephone Number(s)

Healthy Lifestyle

If asked the question – “What do you hold most dear in your life?” – most of us would answer our family and our health. Yet, most people take better care of their cars than they do their bodies.

There are many factors that influence our physical and mental health and overall well-being. A few of these factors include:

- Proper nutrition
- Physical activity
- Stress management
- Adequate sleep

This list is by no means exhaustive but will serve as a starting point in the discussion of the foundation of health as well as an integrated approach to pain management.

As you embark on your journey to a “healthier you” remember to prioritize, set limits and pace yourself!



Nutrition

Good nutrition is vital to good health. Specific diseases and conditions linked to poor diet include cardiovascular disease, hypertension, type 2 diabetes, overweight and obesity, osteoporosis, constipation, diverticular disease, iron deficiency anemia, oral disease, malnutrition, and some cancers. Many of these conditions have a pain component.

Each major food group provides a variety of nutrients, so it's important to include all food groups in your daily eating plan while not exceeding recommended caloric intake. There is a great deal of information out there, but identifying a food plan that's right for you often presents a challenge.

The next few pages point to just a few resources that may provide some insight on dietary needs and nutrition guidance from the United States Department of Agriculture.

This is just a starting point, however. Be sure to talk with your health care team before starting a diet or changes in your eating habits. Also, check with your pharmacist for potential interactions between food and medications.

Websites like www.ChooseMyPlate.gov provide resources like the tip sheet on the next page, as well as tools to help track food choices and activity levels. This can be a great way to learn more about positive changes that you can make toward wellness every day!



10
tips

Nutrition
Education Series

choose MyPlate

10 tips to a great plate



Making food choices for a healthy lifestyle can be as simple as using these 10 Tips.

Use the ideas in this list to *balance your calories*, to choose foods to *eat more often*, and to cut back on foods to *eat less often*.

1 balance calories

Find out how many calories YOU need for a day as a first step in managing your weight. Go to www.ChooseMyPlate.gov to find your calorie level. Being physically active also helps you balance calories.

2 enjoy your food, but eat less

Take the time to fully enjoy your food as you eat it. Eating too fast or when your attention is elsewhere may lead to eating too many calories. Pay attention to hunger and fullness cues before, during, and after meals. Use them to recognize when to eat and when you've had enough.



3 avoid oversized portions

Use a smaller plate, bowl, and glass. Portion out foods before you eat. When eating out, choose a smaller size option, share a dish, or take home part of your meal.

4 foods to eat more often

Eat more vegetables, fruits, whole grains, and fat-free or 1% milk and dairy products. These foods have the nutrients you need for health—including potassium, calcium, vitamin D, and fiber. Make them the basis for meals and snacks.



5 make half your plate fruits and vegetables

Choose red, orange, and dark-green vegetables like tomatoes, sweet potatoes, and broccoli, along with other vegetables for your meals. Add fruit to meals as part of main or side dishes or as dessert.

6 switch to fat-free or low-fat (1%) milk

They have the same amount of calcium and other essential nutrients as whole milk, but fewer calories and less saturated fat.



7 make half your grains whole grains

To eat more whole grains, substitute a whole-grain product for a refined product—such as eating whole-wheat bread instead of white bread or brown rice instead of white rice.

8 foods to eat less often

Cut back on foods high in solid fats, added sugars, and salt. They include cakes, cookies, ice cream, candies, sweetened drinks, pizza, and fatty meats like ribs, sausages, bacon, and hot dogs. Use these foods as occasional treats, not everyday foods.

9 compare sodium in foods

Use the Nutrition Facts label to choose lower sodium versions of foods like soup, bread, and frozen meals. Select canned foods labeled "low sodium," "reduced sodium," or "no salt added."



10 drink water instead of sugary drinks

Cut calories by drinking water or unsweetened beverages. Soda, energy drinks, and sports drinks are a major source of added sugar, and calories, in American diets.

USDA
Center for Nutrition
Policy and Promotion

Go to www.ChooseMyPlate.gov

DG TipSheet No. 1

June 2011

USDA is an equal opportunity
provider and employer.



Physical Activity

If you live with pain, the thought that exercise might help can seem contrary. After all, if you're hurting, you have a built-in excuse to avoid taking the stairs, taking a walk or hitting the gym. It used to be that doctors thought that exercise might worsen painful symptoms or accelerate the disease. So doctors encouraged patients to seek rest, not activity. But scientific studies have shown that, for most people, range of motion, strengthening, and aerobic conditioning exercises are safe and necessary.¹⁴ In addition to the numerous other benefits that exercise provides, it can also help people who suffer from a number of painful conditions, including chronic neck disorders, osteoarthritis, rheumatoid arthritis, fibromyalgia, myofascial pain, and chronic low back pain.¹⁵

People of all ages, shapes, sizes, and abilities can benefit from being physically active. The more physical activity you do, the greater the health benefits. Being physically active can help you:¹⁶

- Increase your chances of living longer
- Feel better about yourself
- Decrease your chances of becoming depressed
- Sleep well at night
- Move around more easily

Some types of physical activity are especially beneficial¹⁶

- Aerobic activities make you breathe harder and make your heart beat faster. Aerobic activities can be moderate or vigorous in their intensity. Vigorous activities take more effort than moderate ones. For moderate activities, you can talk while you do them, but you can't sing. For vigorous activities, you can only say a few words without stopping to catch your breath.
- Muscle-strengthening activities make your muscles stronger. These include activities like push-ups and lifting weights. It is important to work all the different parts of the body – your legs, hips, back, chest, stomach, shoulders, and arms.
- Bone-strengthening activities make your bones stronger. Bone strengthening activities, like jumping, produce a force on the bones that promotes bone growth and strength.
- Balance and stretching activities enhance physical stability and flexibility, which reduces risk of injuries. Examples are gentle stretching, dancing, yoga, martial arts, and t'ai chi.



Stress Management

Scientists have been studying the psychological and physical impact of stress for decades. The following information is a brief summary of some of the most important aspects of stress, how it affects our health and what we can do to try to deal with the aftermath.

When stressful events occur, we spend time and energy dealing with the situation and we draw our efforts away from other aspects of life that need our attention. As a result, we often let our unhealthy habits re-surface. For example, people may lose sleep, eat poorly, stop exercising and increase smoking and alcohol consumption. These behaviors are unhealthy and put a tremendous strain on our bodies, not to mention make us less likely to deal with stress effectively.

Stress is inevitable but can be managed.

The next few pages include tools and techniques to help assess and manage stress.

See the next page to take the Recent Life Changes Questionnaire. If you are concerned about the effects of stress on your pain, fill this out and discuss the results with your health care provider.



Recent Life Changes Questionnaire (RLCQ)

The following Recent Life Changes Questionnaire (RLCQ)¹⁷ is a list of possible “normal” life events. Simply add up the numbers on the right of each event that has occurred in your life in the last 6 months. A 6-month score of 300 or more, or a 12-month score of 500 or more, indicates high stress in your life.

Health

An illness or injury that kept you in bed for more than a week or sent you to the hospital	74	<input type="checkbox"/>
An illness or injury that was less serious than above	44	<input type="checkbox"/>
Major dental work	26	<input type="checkbox"/>
Major change in eating habits	27	<input type="checkbox"/>
Major change in sleeping habits	26	<input type="checkbox"/>
Major change in your usual type and/or amount of recreation	28	<input type="checkbox"/>

Work

Change to a new type of work	51	<input type="checkbox"/>
Change in your work hours or conditions	35	<input type="checkbox"/>
More work responsibilities	29	<input type="checkbox"/>
Fewer work responsibilities	21	<input type="checkbox"/>
A promotion	31	<input type="checkbox"/>
A demotion	42	<input type="checkbox"/>
A transfer	32	<input type="checkbox"/>
Trouble with your boss	29	<input type="checkbox"/>
Trouble with your coworkers	35	<input type="checkbox"/>
Trouble with those you supervise	35	<input type="checkbox"/>
Other work troubles	28	<input type="checkbox"/>
Major business readjustment	60	<input type="checkbox"/>
Retirement	52	<input type="checkbox"/>
Laid off	68	<input type="checkbox"/>
Fired	79	<input type="checkbox"/>
Took a course to help your work	18	<input type="checkbox"/>

Home and family

Major change in living conditions	42	<input type="checkbox"/>
Move within same city or town	25	<input type="checkbox"/>
Move to different town, city, or state	47	<input type="checkbox"/>
Change in family get-togethers	25	<input type="checkbox"/>
Major change in health or behavior of a family member	55	<input type="checkbox"/>
Marriage	50	<input type="checkbox"/>
Pregnancy	67	<input type="checkbox"/>
Miscarriage or abortion	65	<input type="checkbox"/>
Birth of a child	66	<input type="checkbox"/>
Adoption of a child	65	<input type="checkbox"/>
Relative moves in with you	59	<input type="checkbox"/>
Spouse begins or stops work	46	<input type="checkbox"/>
Child leaves home to attend college	41	<input type="checkbox"/>
Child leaves home due to marriage	41	<input type="checkbox"/>
Child leaves home for other reasons	45	<input type="checkbox"/>
Change in arguments with spouse	50	<input type="checkbox"/>
Problems with relatives or in-laws	38	<input type="checkbox"/>
Parents divorce	59	<input type="checkbox"/>
A parent remarries	50	<input type="checkbox"/>
Separation from spouse due to work	53	<input type="checkbox"/>
Separation from spouse due to marital difficulties	76	<input type="checkbox"/>
Divorce	96	<input type="checkbox"/>
Birth of grandchild	43	<input type="checkbox"/>
Death of spouse	119	<input type="checkbox"/>
Death of child	123	<input type="checkbox"/>
Death of parent	100	<input type="checkbox"/>
Death of a brother or sister	102	<input type="checkbox"/>

Recent Life Changes Questionnaire (RLCQ) *continued*

Personal and social		Financial			
Change in personal habits	26	<input type="checkbox"/>	Major increase in income	38	<input type="checkbox"/>
Beginning or ending school	38	<input type="checkbox"/>	Major loss of income	60	<input type="checkbox"/>
Change of school or college	35	<input type="checkbox"/>	Investment and/or credit difficulties	56	<input type="checkbox"/>
Change in political beliefs	24	<input type="checkbox"/>	Loss/damage to personal property	43	<input type="checkbox"/>
Change in religious beliefs	29	<input type="checkbox"/>	Moderate purchase	20	<input type="checkbox"/>
Change in social activities	27	<input type="checkbox"/>	Major purchase	37	<input type="checkbox"/>
Vacation	24	<input type="checkbox"/>	Foreclosure on mortgage or loan	58	<input type="checkbox"/>
New, close personal relationship	37	<input type="checkbox"/>			
Engagement to marry	45	<input type="checkbox"/>			
Girlfriend or boyfriend problems	39	<input type="checkbox"/>			
Sexual difficulties	44	<input type="checkbox"/>			
“Falling out” of a close personal relationship	47	<input type="checkbox"/>			
An accident	48	<input type="checkbox"/>	Health subtotal		<input type="checkbox"/>
Minor violation of the law	20	<input type="checkbox"/>	Work subtotal	+	<input type="checkbox"/>
Being held in jail	75	<input type="checkbox"/>	Home and family subtotal	+	<input type="checkbox"/>
Death of a close personal friend	70	<input type="checkbox"/>	Personal and social subtotal	+	<input type="checkbox"/>
Major decision about immediate future	51	<input type="checkbox"/>	Financial subtotal	+	<input type="checkbox"/>
Major personal achievement	36	<input type="checkbox"/>	TOTAL	=	<input type="checkbox"/>

Stress Management Techniques

Emotional stress usually occurs in situations people consider difficult or challenging. People may feel stressed in different situations.

Physical stress is a physical reaction of the body to various triggers. The pain experienced after surgery is an example of physical stress. Physical stress often leads to emotional stress, and emotional stress often occurs in the form of physical stress (e.g., stomach cramps).

Stress management involves controlling and reducing the tension that occurs in stressful situations by making emotional and physical changes. The degree of stress and the desire to make the changes will determine how much improvement takes place.

Studies show that exercise helps restore the body's neurochemical balance and triggers a positive emotional state. Not only does regular exercise slow down the heart-racing adrenaline associated with stress, but it also boosts levels of natural endorphins – pain-fighting molecules that may be responsible for the well-known “runner’s high.” Endorphins help to reduce anxiety, stress, and depression.¹⁴

The National Institutes of Health makes the following suggestions:¹⁸

Make an effort to stop negative thoughts:

- Find the positive in situations, do not dwell on the negative
- Plan fun activities
- Take regular breaks

Physical activity:¹⁸

- Start a physical activity program. Most experts recommend 150 minutes of aerobic activity per week.
- Decide on a specific time, type, amount, and level of physical activity. Fit this time into your schedule so it can be part of your routine.
- Find a buddy to exercise with – it is more fun and it will encourage you to stick with your routine.
- You do not have to join a gym – 20 minutes of brisk walking outdoors will do the trick.





Social support:¹⁸

- Make an effort to interact socially with people. Even though you feel stressed, you will be glad to meet your friends, if only to get your mind off of things.
- Nurture yourself and others.
- Reach out to other people through support groups, which can be in-person or online.

Nutrition:¹⁸

- Plan to eat foods that improve your health and well-being. For example, increase the amount of fruits and vegetables you eat.
- Use resources like ChooseMyPlate.gov to help you learn about making healthy food choices.
- Eat the right amount of food on a regular schedule.

Relaxation:¹⁸

- Learn about and try using one or more of the many relaxation techniques, such as guided imagery, listening to music, or practicing yoga or meditation. One or more of these techniques should work for you.
- Listen to your body.
- Take a mini retreat.
- Take time for personal interests and hobbies.

Talk with Your Health Care Professional:

If these stress management techniques do not work for you, there are professionals, such as licensed social workers, psychologists, and psychiatrists, who can help. Schedule time with one of these mental health professionals to help you learn stress management strategies, including relaxation techniques.

Sleep

Pain is one of many detractors from a good night's sleep. The National Sleep Foundation reports that two-thirds of chronic pain sufferers experience sleep problems. When a chronic pain sufferer experiences interrupted sleep, a vicious cycle ensues – sleep disruption caused by chronic pain exacerbates the pain, which in turn interrupts sleep.¹⁹

Like eating well and being physically active, getting a good night's sleep is vital to your well-being. Until the 1950s, most people thought of sleep as a passive, dormant part of our daily lives. We now know that our brains are very active during sleep. Moreover, sleep affects our daily functioning and our physical and mental health in many ways that we are just beginning to understand.²⁰

According to a National Sleep Foundation survey, an estimated 40% of Americans sleep less than seven hours a night on weekdays and 71% sleep less than eight hours a night on weekdays.²¹

Chronic sleep deprivation may:

- Raise the risk of cardiovascular disease, depression, diabetes and obesity
- Impair cognitive function, memory, and the immune system
- Change metabolism, so that people eat more and store fat

The National Institutes of Health (NIH) has published a document titled “Your Guide to Healthy Sleep.” This document provides information about sleep disorders such as snoring, sleep apnea, insomnia, restless leg syndrome, and narcolepsy.

Tips from the NIH “Your Guide to Healthy Sleep”²²

- Stick to a sleep schedule.
- Exercise is great but not too late in the day.
- Avoid caffeine and nicotine.
- Avoid alcoholic drinks before bed.
- Avoid large meals and beverages late at night.
- Avoid medicines that delay or disrupt your sleep, if possible.
- Don't take naps after 3 p.m.
- Relax before bed.
- Take a hot bath before bed.
- Have a good sleeping environment.
- Have the right sunlight exposure.
- Don't lie in bed awake.
- See a doctor if you continue to have trouble sleeping.



A more detailed explanation of these helpful tips can be found at www.nhlbi.nih.gov/health/public/sleep/healthysleepfs.pdf

Sleep Evaluation Tool

This is a series of True/False questions. It will help reveal any problems in your pattern of sleep. It will also look at how your sleep affects you during the day.

Read the statements below. Answer true or false for each one. If you answer true more than twice, you may want to discuss your sleep problem with your health care professional.

SITUATION	TRUE	FALSE
I feel sleepy during the day, even when I get a good night's sleep.		
I get very irritable when I can't sleep.		
I often wake up at night and have trouble falling back to sleep.		
It usually takes me a long time to fall asleep.		
I often wake up very early and can't fall back to sleep.		
I experience an uncomfortable/restless sensation in my legs at night.		
My legs often move or jerk during the night.		
I sometimes wake up gasping for breath.		
My bed partner says my snoring keeps her/him from sleeping.		
I've fallen asleep driving.		

To view or download a copy of this tool, visit the American Academy of Sleep Medicine at <http://yoursleep.aasmnet.org/SleepEval.aspx>.

Your Pain Care **Resources:** General

American Cancer Society
800-ACS-2345 (800-227-2345)
www.cancer.org

American Chronic Pain Association
800-533-3231
www.theacpa.org

American Society of Law,
Medicine and Ethics
617-262-4990
www.aslme.org

Amputee Coalition of America
888-267-5669
www.amputee-coalition.org

Arthritis Foundation
800-283-7800
www.arthritis.org

Caregiver Action Network
202-772-5050
www.caregiveraction.org

C-Change
202-349-0902
www.c-changetogether.org

Center for Practical Bioethics
800-344-3829
www.practicalbioethics.org

Citizen Advocacy Center
630-833-4080
www.citizenadvocacycenter.org

Dia de la Mujer Latina, Inc.
281-489-1111
www.diadelamujerlatina.org

Disabled American Veterans
877-426-2838
www.dav.org

Ehlers-Danlos National Foundation
703-506-2892
www.ednf.org

Ehlers-Danlos Syndrome Network C.A.R.E.S
262-514-2851
www.ehlersdanlosnetwork.org

Hospice Foundation of America
800-854-3402
www.hospicefoundation.org

Interstitial Cystitis Association
703-442-2070
www.ichelp.org

LIVESTRONG Foundation
877-236-8820
www.livestrong.org

The Leukemia & Lymphoma Society
914-949-5213
www.lls.org

National Fibromyalgia & Chronic Pain Association
801-200-3627
www.fmcpaware.org

National Organization for Rare Disorders
203-744-0100
www.rarediseases.org

National Stroke Association
800-STROKES (800-787-6537)
www.stroke.org

National Vulvodynia Association
301-299-0775
www.nva.org

National Women's Health Resource Center
877-986-9472
www.healthywomen.org

Pancreatic Cancer Action Network
877-272-6226
www.pancan.org

Patient Alliance for Neuroendocrineimmune
Disorders Organization for Research and Advocacy
231-421-8350
www.pandoraorg.net

Patient Advocate Foundation
800-532-5274
www.patientadvocate.org

Prostate Net
201-289-8221
www.prostate-online.com

Power of Pain
480-882-1342
www.powerofpain.org

Your Pain Care **Resources:** General

Reflex Sympathetic Dystrophy
Syndrome Association
877-662-7737
www.rsds.org

Sickle Cell Disease Association of America
800-421-8453
www.sicklecelldisease.org

Society for Women's Health Research
202-223-8224
www.womenshealthresearch.org

Susan G. Komen for the Cure
877-465-6636
ww5.komen.org

TMJ Association
www.tmj.org

U.S. Pain Foundation
800-910-2462
www.uspainfoundation.org

Your Pain Care **Resources:** Health Care Providers

Nurses

American Association of Nurse Practitioners
512-442-4262
www.aanp.org

American Society for
Pain Management Nursing
888-342-7766
www.aspmn.org

Association of Rehabilitation Nurses
800-229-7530
www.rehabnurse.org

Hospice and Palliative Nurses Association
412-787-9301
www.hpna.org

Nurse Practitioner Healthcare Foundation
425-861-0911
www.nphealthcarefoundation.org

National Association Directors of Nursing
Administration in Long Term Care
800-222-0539
www.nadona.org

Oncology Nursing Society
866-257-4667
www.ons.org

Pharmacists

American Pharmacists Association
800-237-2742
www.pharmacist.com

American Society of
Consultant Pharmacists
800-355-2727
www.ascp.com

National Community Pharmacists Association
703-683-8200
www.ncpanet.org

Physicians

American Academy of Family Physicians
800-274-2237
www.aafp.org

American Academy of Hospice
and Palliative Medicine
847-375-4712
www.aahpm.org

American Academy of Neurology
800- 879-1960
www.aan.com

American Academy of Pain Medicine
847-375-4731
www.painmed.org

Your Pain Care **Resources:** Health Care Providers

American Academy of Physical Medicine
and Rehabilitation
847-737-6000
www.aapmr.org

American College of
Osteopathic Family Physicians
800-323-0794
www.acofp.org

American College of Physicians
800-523-1546
www.acponline.org

American College of Rheumatology
404-633-3777
www.rheumatology.org

American Geriatrics Society
212-308-1414
www.americangeriatrics.org

American Medical Directors Association
800-876-2632
www.amda.com

American Medical Association
800-621-8335
www.ama-assn.org

American Osteopathic Association
800-621-1773
www.osteopathic.org

American Psychiatric Association
888-35-77924
www.psych.org

American Society of Anesthesiologists
847-825-5586
www.asahq.org

American Society of Clinical Oncologists
571-483-1300
www.asco.org

American Society of Regional
Anesthesia and Pain Medicine
855-795-2772
www.asra.com

American Academy of
Orthopaedic Surgeons
847-823-7186
www.aaos.org

Social Workers

Association of Oncology Social Work
847-480-6343
www.aosw.org

National Association of Social Workers
202-408-8600
www.socialworkers.org

Other/Multidisciplinary

American Academy of Pain Management
209-533-9744
www.aapainmanage.org

American Academy of Physician Assistants
703-836-2272
www.aapa.org

American Chiropractic Association
703-276-8800
www.acatoday.org

American Occupational Therapy Association
301-652-6611
www.aota.org

American Physical Therapy Association
800-999-2782
www.apta.org

American Pain Society
847-375-4715
www.americanpainsociety.org

Case Management Society of America
800-216-2672
www.cmsa.org

Mental Health America
800-969-6642
www.mentalhealthamerica.net

National Hospice and
Palliative Care Organization
703-837-1500
www.nhpco.org

University of Wisconsin Pain and Policy Study Group
608-263-7662
www.painpolicy.wisc.edu

U.S. Food and Drug Administration
888-463-6332
www.fda.gov

Your Pain Care **Resources:** Healthy Lifestyle

American Dietetic Association

800-877-1600

www.eatright.org

American Heart Association

800-242-8721

www.heart.org

American Sleep Apnea Association

888-293-3650

www.sleepapnea.org

American Sleep Association

www.sleepassociation.org

Arizona Center for Integrative Medicine

520-626-6489

<http://integrativemedicine.arizona.edu>

Centers for Disease Control and Prevention

800-232-4636

www.cdc.gov/nccdphp/dnpa

The Chuckle Channel

www.chucklechannel.com

Massachusetts General Hospital Benson-Henry

Institute For Mind Body Medicine

617-643-6090

www.massgeneral.org/bhi

National Center for Complimentary
and Alternative Medicine

888-644-6226

<http://nccam.nih.gov>

National Consumers League

202-835-3323

www.nclnet.org

National Institute on Drug Abuse

301-443-1124

www.drugabuse.gov

National Heart Lung and Blood Institute

301-592-8573

www.nhlbi.nih.gov

National Sleep Foundation

703-243-1697

www.sleepfoundation.org

Partnership to Fight Chronic Disease

www.fightchronicdisease.org

Substance Abuse and Mental

Health Services Administration

877-726-4727

www.samhsa.gov

Talk About Sleep

www.talkaboutslee.com

University of Massachusetts Medical School,

Center for Mindfulness

508-856-2656

www.umassmed.edu/cfm

United States Department of Agriculture

202-720-2791

www.usda.gov

U.S. Department of Health and

Human Services

877-696-6775

www.hhs.gov

WebMD

[www.webmd.com/back-pain/america-asks-13/
back-pain-and-sleep](http://www.webmd.com/back-pain/america-asks-13/back-pain-and-sleep)





Take an Active Role: Focus on Caregiving

Most of us will find ourselves in the role of a caregiver or in need of a caregiver at some point in our lives. It may be taking care of a sick child, spouse, or perhaps a friend. Regardless of whom you are caring for or how you came to be a caregiver, the role is not an easy one.

The next few pages will address:

- Family Caregivers
- Caring for Those who Suffer from Pain
- Caring for Those at End of Life
- Caring for the Caregiver
- Special Considerations for Seniors
- Resources

Family Caregivers

What is a family caregiver?

According to the Department of Pain Medicine and Palliative Care at Beth Israel Hospital in New York, a family caregiver is “anyone who provides any type of physical and/or emotional care for an ill or disabled loved one at home.” For this definition, “family” refers to a nonprofessional who is called “family” by the person who is sick. Sometimes, family is whoever shows up to help.²³

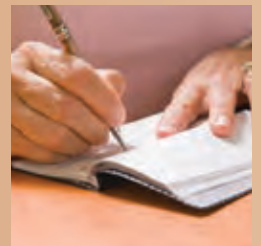
Caregivers can be:

- Parents
- Adult children
- Spouses
- Family members
- Neighbors
- Friends



Caregiver tasks can include any of the following:

- Helping with personal and/or medical care
- Household chores
- Assisting with transportation
- Overseeing finances
- Providing emotional support



Caring for Those who Suffer from Pain

The biggest fear of chronically ill patients and their families is that the patient will suffer with unrelieved pain. Many people do not tell others how much pain they feel for a variety of reasons: they believe that they are not supposed to have pain, they think that pain is a sign of weakness, or they assume that nothing can be done.²⁴

Pain is subjective so it's impossible to know what another person's pain feels like. The important thing is to believe the care recipient when he/she reports pain. For a number of reasons, people often don't like to "complain" or admit they are in pain so don't be afraid to encourage your loved one to discuss their pain. You can start the conversation by using some of the pain assessment tools in the first section of this Handbook.



In order to promote appropriate pain management, it is important for you to recognize if your loved one is in pain.

Your loved one may be in pain if he/she:²⁴

- has decreased appetite
- has lost interest in regular activities
- is crying and upset about discomfort
- grimaces or winces when moving
- stays in bed and doesn't get dressed
- has difficulty sleeping
- is tense and tries to avoid movement

One way you can help your loved one is by acting as his or her advocate.



Caring For Those at End of Life

As a family caregiver, you may be involved in making serious medical decisions and having some very difficult conversations. In light of this, no matter what your age or health condition, it is important to think about how you and your loved ones want to be cared for during the last months/days of your lives.

In preparing for this conversation some terms that you should be familiar with are:

- Informed consent
- Palliative care
- Advanced directives
- Hospice care
- Healthcare proxy
- End of life care
- Living will

The Center for Practical Bioethics has developed a workbook called “Caring Conversations” that may provide the guidance you need to prepare you for this discussion. Caring Conversations® is designed to guide you, your family and your friends through the process of advance care planning. Each copy of Caring Conversations includes a healthcare directive form and a durable power of attorney for health care form.

To order free resources, visit the Center for Practical Bioethics website:
www.practicalbioethics.org/resources/caring-conversations.html



Caring For the Caregiver

How to Support Someone Caring for Another

Many of us know someone who is a caregiver. Do you know someone who spends time providing physical, emotional or practical support to a family member or friend? Many caregivers feel alone, helpless, confused, unprepared, tired and unable to provide for the needs of their family member or friend. Often, people caring for another need help and do not know how to ask for it.²⁵

Tips to help support a caregiver from the National Hospice and Palliative Care Organization:

Ask the caregiver how they are doing

Let them know you respect their privacy, but care about them and want to offer support and a listening ear.

Reach out to caregivers with a touch, a hug, or other physical expression of support

Supportive human contact is important and can be very meaningful to someone who is caregiving and experiencing the many losses that accompany being a caregiver. However it is always important to check with the caregiver to make sure they are okay with being touched.

Spend time with the person who is sick or injured

Family caregivers are often the only link the care receiver has with the outside world. Offering to spend time with the person can be a gift to both the care receiver and caregiver. Bring a book or newspaper to read aloud, a game to play, photos to share or just a friendly ear for a conversation.

Offer specific help

Saying “call me if you need me” is vague and may not appear to be a sincere offer for help. Often caregivers do not want to be a bother or may not feel they have the time to make a call, as it is one more thing for them to do. Be specific, ask the caregiver if you can go shopping, make a phone call, cook a meal or sit with the person who is ill. By offering to do something specific, you are communicating that you are really willing to help the caregiver.

Tell the caregiver it is okay to take a break from their caregiving role

You can let them know that it is okay to take time to renew themselves; they deserve it and need to care for themselves in order to continue providing care.

10

Tips for Family Caregivers²⁶

1

Seek support from other caregivers. You are not alone!

2

Take care of your own health so that you can be strong enough to take care of your loved one.

3

Accept offers of help and suggest specific things people can do to help you.

4

Learn how to communicate effectively with doctors.

5

Caregiving is hard work so take respite breaks often.

6

Watch out for signs of depression and don't delay in getting professional help when you need it.

7

Be open to new technologies that can help you care for your loved one.

8

Organize medical information so it's up to date and easy to find.

9

Make sure legal documents are in order.

10

Give yourself credit for doing the best you can in one of the toughest jobs there is!

For more information and tips on caregiving, visit the Caregiver Action Network at [CaregiverAction.org](https://www.caregiveraction.org).

Special Considerations for Seniors

With the population aging, the need for information surrounding the unique needs of seniors with pain is increasing. Recognizing and communicating pain can be challenging but is not impossible.

The next couple of pages identify organizations and resources that address pain in the elderly from a patient, provider, caregiver and advocate perspective.



Pain in the absence of disease is not a normal part of aging, yet it is experienced daily by a majority of older adults in the United States.²⁷ Given the growing population of people over the age of 65 and studies supporting that elders are among the most undertreated for pain, it is important that attention focus on appropriately managing pain in this population.²⁸



According to the American Geriatric Society, pain is one of the most common complaints among older adults. Between 25 and 50% of older adults living at home, and up to 85% of those living in nursing homes, have significant pain. Most often, the pain is chronic or persistent, and associated with medical conditions such as arthritis or cancer.²⁸

Pain can lead to other problems such as:²⁹

- decreased mobility and the ability to do everyday activities
- increased risk for falls and weight loss
- difficulty sleeping
- poor concentration
- changes in mood and self-image
- difficulties with relationships
- feeling anxious or depressed

On the positive side, most pain can improve with treatment. Therefore, it is important to speak to your health care provider about all your pain issues and develop a treatment plan together.

Today’s seniors are challenging the notion that pain is just a normal part of aging. Healthy habits discussed elsewhere in this Handbook like nutrition, activity and sleep are just as important, if not more so, during the later years.

According to the American Geriatric Society Foundation for Health in Aging, simply living longer isn’t enough. What we really want is to live longer well, staying healthy enough to continue doing the things we love. It’s never too late to make changes that can help you live a longer and healthier life.

Here, from the American Geriatric Society Foundation for Health in Aging, are ten top tips for living longer and better:³⁰

10 Top Tips for Aging Well

1

Eat a rainbow

Eat brightly colored fruits and vegetables.

2

Sidestep Falls

Walking as little as 30 minutes, three times a week can lower your risk of falls.

3

Toast with a smaller glass

Drinking “moderately” changes with age - 1 drink a day for older men and ½ a drink a day for older women (a “drink” is 1 oz of hard liquor, 6 oz of wine, or 12 oz of beer).

4

Know the low-down on sleep in later life

Most older people need 7 or 8 hours of sleep a night.

5

Sharpen your mind

Complex computer games, discussion clubs, learning a new language and engaging in social give-and-take with other people can keep your brain sharp.

6

Enjoy safe sex

More older people are being diagnosed with sexually transmitted diseases: use precaution.

7

Get a medications check

Be sure your health care provider is aware of all medication you are taking including over-the-counter medication, vitamins and any other supplements.

8

Speak up when you feel down or anxious

Tell your health care provider right away if you have lingering sadness, tiredness, loss of appetite or pleasure from doing the things you once enjoyed, difficulty sleeping, worry, irritability, and wanting to be alone much of the time.

9

Get your shots

Must-have vaccines for seniors include those that protect against pneumonia, tetanus/diphtheria, shingles, and the flu.

10

Find the right health care professional and make the most of your visits

See your health care professional regularly, answer his or her questions frankly, ask any questions you have, and follow his or her advice.

Caregiver Resources

Alliance for Aging Research

202-293-2856

www.agingresearch.org

Alzheimer's Association

800-272-3900

www.alz.org

American Association for Geriatric Psychiatry

703-556-9222

www.aagponline.org

American Association of

Nurse Assessment Coordinators

800-768-1880

www.aanac.org

American Association of Retired Persons

888-687-2277

www.aarp.org

American Chronic Pain Association

800-533-3231

www.theacpa.org

American Geriatrics Society/Foundation

for Health in Aging

800-563-4916

www.healthinaging.org

American Medical Directors Association

800-876-2632

www.amda.com

American Public Health Association

202-777-2742

www.apha.org

American Society of Consultant Pharmacists

800-355-2727

www.ascp.com

American Society on Aging

800-537-9728

www.asaging.org

Caregiver Action Network

202-772-5050

www.caregiveraction.org

Centers For Disease Control & Prevention

800-232-4636

www.cdc.gov

Center for Practical Bioethics

800-344-3829

www.practicalbioethics.org

Families USA

202-628-3030

www.familiesusa.org

Family Caregiver Alliance

800-445-8106

www.caregiver.org

Federal Interagency Forum on

Aging-Related Statistics

www.agingstats.gov

Geriatric Pain

319-335-7080

www.geriatricpain.org

Gerontological Society of America

202-842-1275

www.geron.org

LIVESTRONG Foundation

877-236-8820

www.livestrong.org

Leading Age

202-783-2242

www.LeadingAge.org

Lotsa Helping Hands

www.lotsahelpinghands.com

Medicare Rights Center

800-333-4114

www.medicarerights.org

National Academy of Elder Law Attorneys

www.naela.org

National Alliance for Caregiving

www.caregiving.org

National Association Directors of Nursing

Administration in Long Term Care

800-222-0539

www.nadona.org

National Association of Area Agencies on Aging

202-872-0888

www.n4a.org

National Association of Nutrition and

Aging Services Programs

202-682-6899

www.nanasp.org

Caregiver Resources

National Cancer Institute

800-422-6237

www.cancer.gov

National Committee to Preserve

Social Security and Medicare

800-998-0180

www.ncpssm.org

National Council on Aging

202-479-1200

www.ncoa.org

National Hispanic Council on Aging

202-347-9733

www.nhcoa.org

National Hospice and Palliative Care Organization

703-837-1500

www.nhpco.org

National Indian Council on Aging

505-292-2001

www.nicoa.org

National Institute on Aging

800-222-2225

www.nia.nih.gov

National Senior Citizens Law Center

202-289-6976

www.nsclc.org

Resource Centers for Minority

Aging Research

310-794-0910

www.rcmar.ucla.edu

Senior Care Services

www.seniorcareservices.org





Take an Active Role: Focus on Finances

According to the Institute of Medicine, the annual cost of chronic pain in the U.S. is estimated to be a staggering \$560-635 billion, including health care expenses and lost productivity.³¹

On a personal level, we also know that people with pain can face significant financial hardship in paying for health care, particularly if pain has limited abilities to work.

This section includes helpful resources including:

- Tips on communicating with insurance companies
- Ways to better understand insurance coverage
- Links to tools to help with insurance company appeals
- Resources for patient assistance programs, the Affordable Care Act (ACA), Medicare, Medicaid, active-duty military and veterans, and workers' compensation

Health Care Expenses

Currently, health care expenses are financed through one or a combination of ways, based on circumstances and eligibility. These include private health insurance, Medicare or Medicaid, state-based workers' compensation programs or active-duty military or Veterans Health Administration. Since the passage of the Affordable Care Act, this also includes state-based health insurance exchanges.

Within each of these programs, there are an often overwhelming array of policies, regulations and procedures that dictate coverage of pain treatments. As you're likely aware, just because a physician recommends a certain course of treatment or medication does not mean that an insurer will cover those costs. For people with pain and their caregivers, this may mean that you have to work harder to ensure access to benefits that you are entitled to through appeals or working to change policies.

By understanding how your insurance plan operates, you may be in a better position to advocate for improved pain care. It is also important to be aware of cost-saving strategies that insurers use that may affect pain treatment. Caregivers and health care professionals can also advocate for improved access on behalf of themselves and their loved ones.

The next few pages provide tips, tools and resources to help you navigate your health insurance plan and to help guide you through interactions with your insurance company personnel.



Communicating Effectively with Insurance Company Personnel

The Caregiver Action Network has created a program about communicating effectively with health care professionals. The program and tool kit can be downloaded here:

<http://my.brainshark.com/Saturing-Communicating-Effectively-With-Healthcare-Professionals-962681677>

It includes tips such as the following:³²

Talking with Insurance Personnel

Before you pick up the phone to speak to a claims representative, you need to gather some information. Be prepared to give the person you talk with:

- Your name and your relationship to your care recipient
- Your care recipient's birth date
- The insurance policy number
- The name and address of the organization that sent the bill
- The total amount of the bill
- The diagnosis code on the bill
- The Explanation of Benefits (if you are questioning an insurance payment)



When you start the conversation, ask for the name and telephone extension of the individual who is handling your phone call. If you need to call again, you will want to try to speak with the same person.

Keep in mind that billing office personnel and insurance claims representatives are there to serve you. You are the customer. Be assertive. You should expect to:

- Be treated with respect and consideration
- Have your concerns clarified
- Have your questions answered with accurate and timely information
- Be informed of any steps you need to take to move things along

Communication Tips

Here are some tips for communicating effectively with people who work in the health insurance system.

- **Be Prepared.** Before you call an insurance company, write down a list of the questions you have so you can handle everything in one phone call.
- **Take Good Notes.** Take notes about your phone conversations, including the date of the call and the information you were given.
- **Be Clear and Concise.** State clearly and briefly what your question or concern is, what you need, and what you expect.
- **Be Patient.** Health insurance issues are frustrating and time-consuming. Accept that you will spend a certain amount of time navigating through automated telephone menus, waiting on hold and waiting for the claims process to be completed.
- **Be Considerate.** Most insurance personnel want to do their jobs well, and they have a tough job to do. Thank them when they have been helpful. Speak to them kindly. Assume that they are trying to help you, not that they are “the enemy.”

The Patient Advocate Foundation

The Patient Advocate Foundation (PAF) has created several brochures that will give you a better understanding of your insurance plan as well as discuss the cost of health care treatments with your provider. For more information, go to: www.patientadvocate.org.



These brochures can be downloaded for free from PAF:

<http://www.patientadvocate.org/requests/publications/GU-Healthcare-Costs-For-Patients.pdf>

<http://www.patientadvocate.org/requests/publications/GU-Understanding-Insurance-Plan.pdf>

Medicare Beneficiaries

The National Pharmaceutical Council (NPC) has developed “Resources for Medicare Beneficiaries: Using Your Medicare Drug Plan – What to Do if Your Medicine Isn’t Covered.”

This 12-page publication helps Medicare Part D recipients and caregivers understand some of the challenges involved in navigating the Medicare prescription drug system, such as:

- How to request coverage of medication under a particular Medicare plan
- When to appeal if a Medicare plan denies coverage of a particular medication
- How to determine who will serve as an appointed representative
- The steps to follow in the appeal process

This brochure includes a sample letter of appeals for Medicare beneficiaries. For more information, visit: www.npcnow.org.

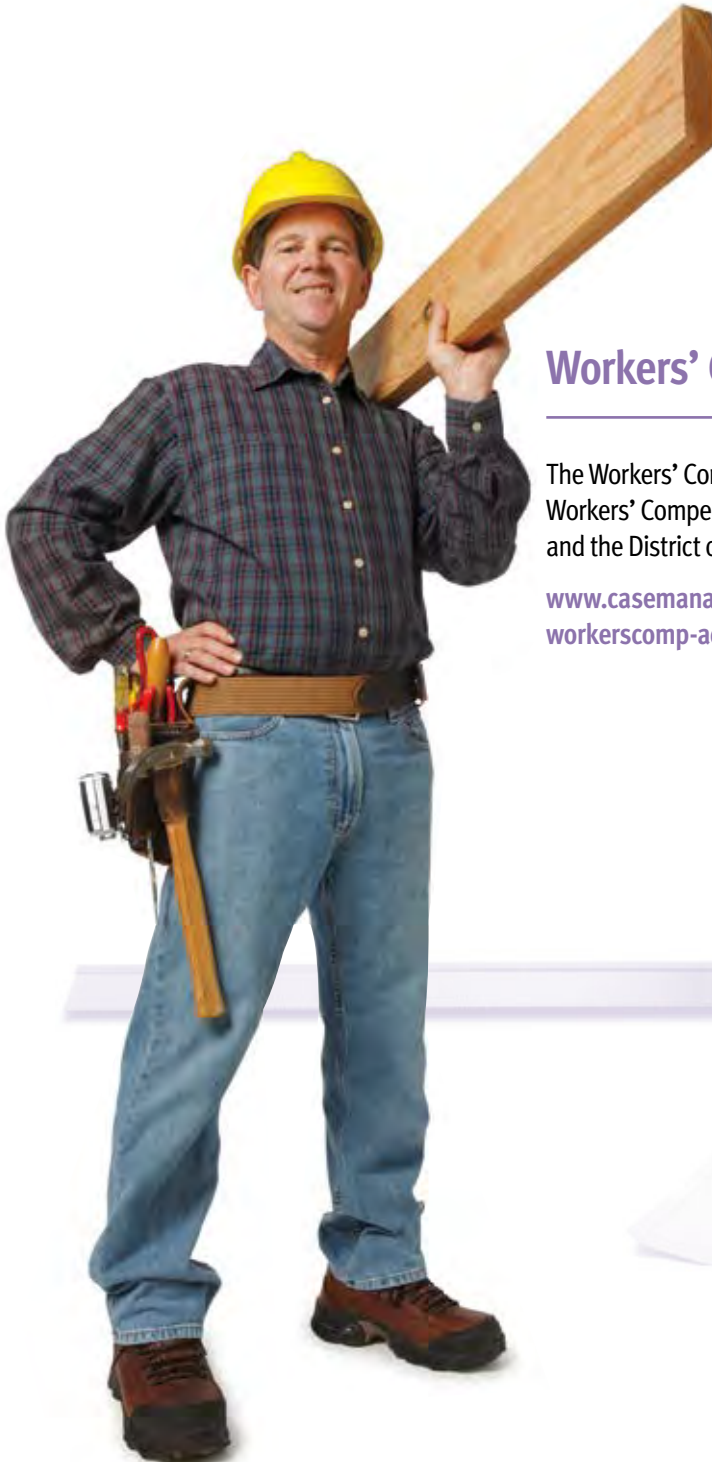
The National Council on Aging has created the resource, “My Medicare Matters.” This website offers information about Medicare, considerations when selecting or switching a Medicare Part D prescription benefit plan, and staying healthy. More information can be found at: www.mymedicarematters.org.

Finally, the UnitedHealthcare website, www.medicaremadeclear.com, includes information about enrollment periods. Through a series of questions, the site guides candidates through scenarios that can affect what type of Medicare coverage plan might be right for them, and important information about cost.

Active Duty Military & Veterans

TRICARE is the health care program for active duty members and their families, retired service members and their families, National Guard/ Reserve members and their families, survivors and others entitled to Department of Defense medical care. The program is a component of the Military Health System. For more information, visit www.tricare.mil.

The Veterans Administration offers comprehensive health care and other benefits for veterans and dependents of active-duty, retired or deceased members of the military. Call 1-800-827-1000 or visit www.va.gov for more information.



Workers' Compensation

The Workers' Compensation Administrators Directory lists Workers' Compensation home page links for all 50 states and the District of Columbia. This can be found here:

www.casemanagement.com/casemanagers/reference/workerscomp-administrators.html



The Affordable Care Act

A central goal of the Affordable Care Act (ACA) is to significantly reduce the number of uninsured by providing a continuum of affordable coverage options through Medicaid and Health Insurance Exchanges.

The federal government website HealthCare.gov (www.HealthCare.gov) provides information that helps explain health insurance information, and provides a tool to find insurance options based on location, age and circumstances.

The Kaiser Family Foundation (www.kff.org) has developed a tool to help illustrate health insurance premiums and subsidies for people purchasing insurance on their own in new health insurance exchanges (or “Marketplaces”) created by the ACA. Beginning in October 2013, middle-income people under age 65, who are not eligible for coverage through their employer, Medicaid, or Medicare, can apply for tax credit subsidies available through state-based exchanges.

Additionally, states have the option to expand their Medicaid programs to cover all people making up to 138% of the federal poverty level (which is about \$33,000 for a family of four). In states that opt out of expanding Medicaid, some people making below this amount will still be eligible for Medicaid, some will be eligible for subsidized coverage through Marketplaces, and others will not be eligible for subsidies. With this calculator, you can enter different income levels, ages, and family sizes to get an estimate of your eligibility for subsidies and how much you could spend on health insurance. As premiums and eligibility requirements may vary, contact your state’s Medicaid office or exchange with enrollment questions.³³

Both HealthCare.gov and the Kaiser Family Foundation websites include current information on status of health exchange programs on the state level, including providers, structure and fees.



Resources: Focus on Finances

Centers for Medicare & Medicaid Services

www.cms.gov

Kaiser Family Foundation

www.kff.org

National Council on Aging
& Access to Benefits Coalition

www.mymedicarematters.org

National Pharmaceutical Council

202-827-2100

www.npcnow.org

Partnership for Prescription Assistance

www.pparx.org

Patient Advocate Foundation

800-532-5274

www.patientadvocate.org

RxAssist

www.rxassist.org

Social Security

800-772-1213

www.ssa.gov/prescriptionhelp

TRICARE

North Region 877-874-2273

South Region 800-444-5445

West Region 877-988-9378

www.tricare.mil

U.S. Department of Health & Human Services

800-318-2596

www.healthcare.gov

U.S. Department of Veterans Affairs

800-827-1000

www.va.gov

State Medicaid Website Addresses

Alabama

www.medicaid.alabama.gov

Alaska

<http://dhss.alaska.gov/dpa/Pages/medicaid/default.aspx>

Arizona

www.azahcccs.gov

Arkansas

www.medicaid.state.ar.us

California

www.dhs.ca.gov

Colorado

www.chcpf.state.co.us

Connecticut

www.dss.state.ct.us/dss.htm

Delaware

www.dhss.delaware.gov/dss/medicaid.html

District of Columbia

www.doh.dc.gov

Florida

www.fdhc.state.fl.us

Georgia

www.dch.georgia.gov

Hawaii

<http://hawaii.gov/health>

Idaho

www.healthandwelfare.idaho.gov

Illinois

www2.illinois.gov/hfs/Pages/default.aspx

Indiana

www.in.gov/fssa

Iowa

www.dhs.state.ia.us

Kansas

www.medicaid.gov/medicaid-chip-program-information/by-state/kansas.html

Kentucky

www.chfs.ky.gov

Resources: Focus on Finances

Louisiana
www.dhh.state.la.us

Maine
www.maine.gov/dhhs

Maryland
www.dhmm.state.md.us

Massachusetts
www.mass.gov

Michigan
<http://michigan.gov/mdch>

Minnesota
www.mn.gov/dhs

Mississippi
www.medicaid.ms.gov

Missouri
www.dss.mo.gov/mhd/index.htm

Montana
www.dphhs.mt.gov

Nebraska
<http://dhhs.ne.gov/Pages/default.aspx>

Nevada
www.dhcfp.state.nv.us

New Hampshire
www.dhhs.state.nh.us

New Jersey
www.state.nj.us/humanservices

New Mexico
www.hsd.state.nm.us

New York
www.health.ny.gov

North Carolina
www.ncdhhs.gov/dma

North Dakota
www.nd.gov/dhs

Ohio
<http://medicaid.ohio.gov>

Oklahoma
www.okhca.org

Oregon
www.oregon.gov/DHS/healthplan

Pennsylvania
www.dpw.state.pa.us

Rhode Island
www.dhs.ri.gov

South Carolina
www.scdhhs.gov

South Dakota
<http://dss.sd.gov/medicalservices>

Tennessee
<http://health.state.tn.us>

Texas
www.hhsc.state.tx.us/medicaid

Utah
<http://health.utah.gov/medicaid>

Vermont
<http://ovha.vermont.gov>

Virginia
www.dmas.virginia.gov

Washington
www.hca.wa.gov/medicaid/Pages/index.aspx

West Virginia
www.wvdhhr.org

Wisconsin
www.dhs.wisconsin.gov

Wyoming
<http://health.wyo.gov>



Take an Active Role: Focus on Clinical Trials

Slow enrollment of patients in clinical trials delays the evaluation of drugs, contributes to costs, and raises the financial risks of developing new drugs – but most importantly, delays in research can cost lives. Participating in medical research can be an invaluable contribution to helping to identify new treatments and even cures. However, there are also risks that must be carefully considered, together with your health care provider.

This section provides a basic overview of clinical trials. Points to keep in mind if you are thinking about volunteering for a clinical trial, include:

- What is a clinical trial?
- Who can participate in clinical trials?
- What is informed consent?
- Sample questions to ask your provider about participating in clinical trials
- Resources for more information about participating in clinical trials

Pain Research & Clinical Trials

Research into new ways to treat pain provides more than just new options. It gives people who suffer from pain hope. In the forefront of pain research are scientists supported by the National Institutes of Health (NIH), including the National Institute of Neurological Disorders and Stroke. Other institutes at NIH that support pain research include the National Institute of Dental and Craniofacial Research, the National Cancer Institute, the National Institute of Nursing Research, the National Institute on Drug Abuse, and the National Institute of Mental Health. Developing better pain treatments is the primary goal of all pain research being conducted by these institutes.³⁴

To make better progress against a disease or illness, however, more patients must enroll in clinical trials. There are many promising new agents, which need to be tested as single agents, but also within existing protocols. However, the pool of patients considering clinical trials remains very low, and studies failing to reach enrollment goals are increasing as the number of promising agents increase.³⁵

A clinical trial (also clinical research) is a research study in human volunteers to answer specific health questions. Carefully conducted clinical trials are the fastest and safest way to find treatments that work in people and ways to improve health. Interventional trials determine whether experimental treatments or new ways of using known therapies are safe and effective under controlled environments. Observational trials address health issues in large groups of people or populations in natural settings.³⁶

Who Can Participate in Clinical Trials?³⁶

All clinical trials have guidelines about who can participate. Inclusion/exclusion criteria are the medical or social standards determining whether a person may or may not be allowed to enter a clinical trial. The factors that allow someone to participate in a clinical trial are called “inclusion criteria” and those that prevent someone from participating are called “exclusion criteria.” These criteria are based on such factors as age, gender, the type and stage of a disease, previous treatment history, and other medical conditions. It is important to note that these criteria are not used to reject people personally, but rather to identify appropriate participants and keep them safe. Inclusion/exclusion criteria, which will vary by study, are an important principle of medical research that helps to produce reliable results.

Before joining a clinical trial, a participant must qualify for the study. Some research studies seek participants with illnesses or conditions to be studied in the clinical trial, while others need healthy participants. The inclusion/exclusion criteria help ensure that researchers will be able to answer the questions they plan to study.

What is Informed Consent?

Millions of volunteers participate in government- and industry-sponsored clinical trials each year. Prior to agreeing to participate, every volunteer has the right to know and understand what will happen during a clinical trial. This is called informed consent and it is a process that can help you decide whether or not participating in a trial is right for you. CenterWatch has created a brochure called “Understanding the Informed Consent Process” that can be downloaded through their website:

www.centerwatch.com/clinical-trials/understanding-informed-consent.aspx





What questions should be asked before choosing to participate?

Patients considering participating in a clinical trial should talk about it with their health care providers. Potential volunteers should also understand the credentials and experience of the staff and the facility involved in conducting the study.³⁶

Questions to ask a physician or medical caregiver:

- How long will the trial last?
- Where is the trial being conducted?
- What treatments will be used and how?
- What is the main purpose of the trial?
- How will patient safety be monitored?
- Are there any risks involved?
- What are the possible benefits?
- What are the alternative treatments besides the one being tested in the trial?
- Who is sponsoring the trial?
- Do I have to pay for any part of the trial?
- What happens if I am harmed by the trial?
- Can I opt to remain on this treatment, even after termination of the trial?

Resources for Clinical Trials Information

Your health care provider may ask you about participating in a clinical trial. If you find information on a clinical trial that you are considering volunteering for, make sure that you discuss this with your provider. Making the decision to volunteer for medical research is an important one, and made after evaluating all the potential risks and benefits. The following websites provide more information about clinical trial participation and the status of pain-related studies.

ClinicalTrials.gov

ClinicalTrials.gov is a registry and results database of federally and privately supported clinical trials conducted in the United States and around the world. **ClinicalTrials.gov** provides information about a trial's purpose, who may participate, locations, and phone numbers for more details. **ClinicalTrials.gov** currently has more than 177,000 trials with locations in 187 countries, and lists information about more than 16,000 trials related to pain. For more information, visit www.clinicaltrials.gov.

CenterWatch

CenterWatch lists thousands of active clinical trials seeking study volunteers, involving new drugs and devices regulated by the FDA and the Department of Health and Human Services. There are currently more than 700 clinical trials underway for pain and pain-related conditions across the country. Listings are posted across a wide range of medical conditions and are searchable by therapeutic area, disease or geographic location. For more information, visit www.centerwatch.com.

MedlinePlus

MedlinePlus is a web-based information service from the National Library of Medicine. Its “Health Topics” section has extensive information from NIH and other trusted sources on hundreds of diseases and conditions, including a link to clinical trials. It also includes an informative “Clinical Trials” health topic page, with material in Spanish, and an interactive tutorial on clinical trials. For more information, visit www.nlm.nih.gov/medlineplus/clinicaltrials.html.

The National Heart, Lung and Blood Institute

The National Heart, Lung and Blood Institute offers more information and videos about the importance of including children in clinical trials. For more information, visit www.nhlbi.nih.gov/studies/index.htm.

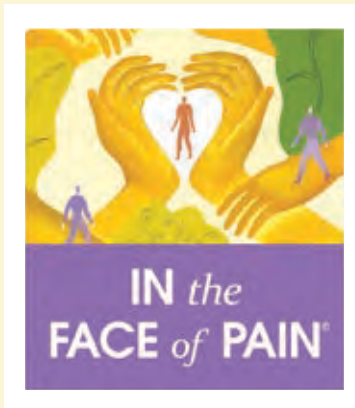
The Patient Advocate Foundation

The Patient Advocate Foundation offers information about clinical trials through its publication, “Lighting the Way: A Practical Guide to Clinical Trials,” which can be accessed here: www.patientadvocate.org/index.php?p=674.

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7. American Chronic Pain Association. Live Better with Pain Log. www.theacpa.org/painLog Accessed October 16, 2014.
8. U.S. Food and Drug Administration. Be an Active Member of Your Health Care Team. www.fda.gov/Drugs/ResourcesForYou/ucm079453.htm Accessed October 16, 2014.
9. National Consumers League. Script Your Future. <http://scriptyourfuture.org/medication-adherence> Accessed October 16, 2014.
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22. National Heart Lung Blood Institute. Your Guide to Healthy Sleep. www.nhlbi.nih.gov/health/public/sleep/healthysleepfs.pdf Accessed October 22, 2014.
23. Department of Pain Medicine and Palliative Care at Beth Israel Hospital. Caregiver Resource Directory – Now You Are a Caregiver. www.netofcare.org/content/default.asp Accessed October 22, 2014.
24. Department of Pain Medicine and Palliative Care at Beth Israel Hospital. Caregiver Resource Directory – Symptom Management at Home. www.netofcare.org/content/default.asp Accessed October 22, 2014.
25. National Hospice and Palliative Care Organization. How to Support Someone Caring for Another. www.caringinfo.org/files/public/brochures/How_to_Support_Someone_Caring_for_Another.pdf Accessed October 22, 2014.
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Notes



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for people with **pain**
a **resource guide** 5th edition

