

Pain Notebook

Three Hole Punch Here

NAME

EMAIL

PHONE

Three Hole Punch Here



GLOBAL
PAIN
INITIATIVE

What is pain?

Pain is a bad sensation that tells you something is wrong. Pain falls into two broad categories: **acute** and **chronic**.

Acute Pain

Acute pain usually lasts a few seconds to several hours, and causes you to stop whatever you are doing and get away from danger. It can be caused by an injury or by a medical procedure, such as surgery. Fortunately, most pain goes away. This pain is often treated with rest, bracing, or medications (such as NSAIDs — Non-Steroidal Anti-Inflammatory Drugs — like ibuprofen, or sometimes narcotics like hydrocodone).

Chronic Pain

Chronic pain lasts way past the time of an illness or injury. It can last from months to years. At times, it can go away completely, or can remain the same. When pain does not go away, it can become a disease. Actually, the *disease* of pain is really a group of many different diseases, each having its own cause and treatment.

Intermittent Pain. This pain occurs in waves or patterns. An example is tennis elbow or low back pain after a lot of activity. Intermittent pain is often treated with changes in activity, NSAIDS, bracing, and/or TENS (an electrical patch you can place on the skin). If the pain is bad, and makes many important activities hard to do, it may be treated with low doses of narcotics.

Persistent Pain. This pain lasts for 12 or more hours every day for more than three months. It can be treated with all sorts of medicines. It can also be treated, in cases of nerve injury, with implantable devices that change the way your nervous system works. In some cases, narcotics are used.

Breakthrough Pain. This pain is different than “all the time pain”. It can happen slowly or very quickly. It **flares up** and “breaks through” the treatments used for your “all the time” pain. It can occur:

- With certain activities you want to do (like walking or sitting),
- Specific activities that you didn’t know were going to happen (like coughing or sneezing),
- Without warning.

This type of pain, if bad, can be treated with specific medicines that are used as needed to bring relief.

PAIN CARE BILL OF RIGHTS

As a person living with pain, you have the right to:

- Have your pain taken seriously and to be treated with *dignity* and *respect* by doctors, nurses, pharmacists, and other healthcare providers.
- Have your pain thoroughly assessed and treated.
- Be informed by your healthcare provider about what may be causing your pain, possible treatments, and the benefits, risks, and potential costs of each.
- Get clear answers to your questions.
- Be allowed time to make decisions that are best for you.
- Be allowed to turn down a particular type of treatment.
- Participate actively in decisions about how to treat your pain.
- Have your pain reassessed regularly and treatment adjusted if your pain has not been controlled.
- Be referred to a pain specialist if your pain persists, or if your pain is not being controlled.

Although not always required by law, these are the rights you should expect for your pain care.



Your healthcare team

The goal in treating pain is to provide relief and allow you to do the things that you enjoy (such as going out with friends) or that you have to do (such as going to work or taking care of your children).

Good pain treatment starts with a conversation with your healthcare provider.

Sometimes, your healthcare provider may ask a pain medicine specialist to assist in helping you figure out the best plan for you. You, your healthcare provider, the pain specialist and other helpers (possibly including friends, family members, and a case worker who knows how to access benefits) form your *healthcare team*. This notebook will show you how you can organize information to have a more effective conversation with that team.

Keep in mind that conversations about your pain are not a one-time thing; they need to happen every time you see your healthcare provider or pain medicine specialist.

Tips for talking with your healthcare team

***You* are the central person in your healthcare team!**

There are several things you can do to keep the other members of your team informed on what's happening with you and your pain:

Be prepared and organized

Use the pain notebook as much as you can. It gives the other members of the team valuable information about your pain experience and how it is affecting you.

Be open and honest

You are the one who feels the pain, and have information that needs to be shared with the whole team.

Don't be afraid or embarrassed to discuss the things that are keeping you from reaching pain relief and improving your social and physical function; sexual activity, sleep, mood, exercise, and social fun are some of the things that allow us to enjoy life.

The members of your team will listen to your concerns, and help you realize your goals.

Prepare questions before seeing a member or members of your team

Often, when you see a member of your healthcare team, you forget important questions that are on your mind. **Write them down!**

A rule of thumb is to write down no more than 2-3 of the questions most important to you for the visit. Take a short amount of time to ask your question(s) so that you get meaningful answer(s).

Make sure you fully understand all explanations of your condition and its treatment

If you do not understand something that is said, ask to hear it again, or in a different way. Ask for learning resources. Is there a website where you can learn more? Is there a video you can watch? Is there another patient who is willing to share their experience?

Make sure you fully understand instructions

If you are not clear about something you should do or a medication you should take to treat your pain; ask your healthcare provider to explain it again or in a different way so that you **do** understand.

Repeat instructions back so that your healthcare provider knows that you understand.

Jot down a few notes to help you remember. If you get home and are unsure about what to do about your pain, call and ask for someone to repeat the instructions to you.

Take notes during your visit

Take notes to remind yourself later of what your team member(s) tell you.

If you have a hard time remembering things, think about bringing a close friend or family member to your visit.

Follow the agreed upon treatment plan

In order to achieve success, ***don't make changes to your agreed upon treatment plan without checking with the other members of your healthcare team.***

If you have significant side effects with a certain treatment, call the member of your healthcare team who is overseeing that part of your treatment and let them know.

If a plan isn't working, make another appointment with the healthcare team member who is overseeing that part of your plan and explain the problem, so that you can come up with a good solution *together*.

Ask a friend or family member to help you stay motivated

Let that person know about the plan you made with your healthcare team. Especially if the pain is very bad, the treatment is difficult or complicated, or pain relief is expected to happen slowly, a friendly supportive voice can help you stay focused and motivated until you feel better. This person can also protect you by helping you follow your treatment plan correctly (like how much medicine to take, and when).

Why Use the Pain Notebook?

You are the expert in what you experience! You know your life and how pain is affecting it.

The **Pain Notebook** will help you keep a simple record of your pain experience over time. Day by Day – it creates a *time capsule* of what you have experienced, and whether your pain is changing for better or worse.

Keeping track of your treatment's progress will help you and your team come up with the *best* ways to treat your pain.

Use your Pain Notebook every day.

How to Use Your Pain Notebook

Use your Pain Notebook in a way that is MOST helpful to YOU

You don't have to be detailed in every part, just the parts that are important for *you*.

Some days, pain flares will make you use it more. Other days, when you are feeling really good, you might forget and only fill it out before you go to bed.

Keep your Pain Notebook in one particular place – one that is easy to remember and allows you to use it.

Find a comfortable place to sit when you put your information into your Pain Notebook using the **DAILY PAIN JOURNAL.**

Keep entries simple – a story doesn't help the other members of your team – remember, **say what is important** and **keep it simple!**

Both sides of one Daily Pain Journal cover a single DAY. Your notebook pain journal pages can be scanned into your medical record and, if you allow it, those pages will help your team serve you better.

The more sections of the daily pages in your **Pain Notebook** you can fill out, the better the picture you can give your team of what you experienced. However, don't feel bad if you have days where you can only make a few entries – it's okay.

If you are finding the pages difficult to complete, *ask someone to help you*. Don't be embarrassed or afraid ... your team members want to know, so that each of them can assist you in reaching your goal of pain relief!

The daily pain journal has several parts; each part is a "piece" of your experience on that particular day, and includes your:

Activity

Function

Mood

Pain and Pain Flares

Sleep

Treatments

At the end of each day, there is a small section where you can make notes of anything else that is GOOD or BAD. This is also a place where you can make quick points to share with your team. The notes in this section can help you ask more helpful questions, the next time you see members of your team.

An example of a completed day in the **Pain Notebook** appears on pages [10 through 13]. The more picture-like you make it, the easier it is for a team member to glance it over to see how you were doing.

A picture is worth a thousand words!

Let's get started

Before you can track your pain and how treatment affects it, you have to put it down on paper.

Using My Pain Diagram:

Mark where your pain is,

Draw lines showing where the pain goes (if it travels elsewhere on your body),

Put down what it feels like (such as 'burning' or 'shooting')

You can use colors (which often helps your team 'see' what you are feeling) as well as shapes. Colors can often be used to show the type of pain (such as headache, arthritis).

We have some suggestions for describing the type of pain, using shapes:

Aching	=	XXXXXX
Burning	=	-----
Cramping	=	ccccc
Sensitive	=	sssss
Shooting	=	↓↓↓
Stabbing	=	////
Stiffening	=	^^^^^
Stinging	=	####
Tingling	=	ttttt

Although most people's pain changes depending on the time of day and activities, put it all down to show what your pain typically is.

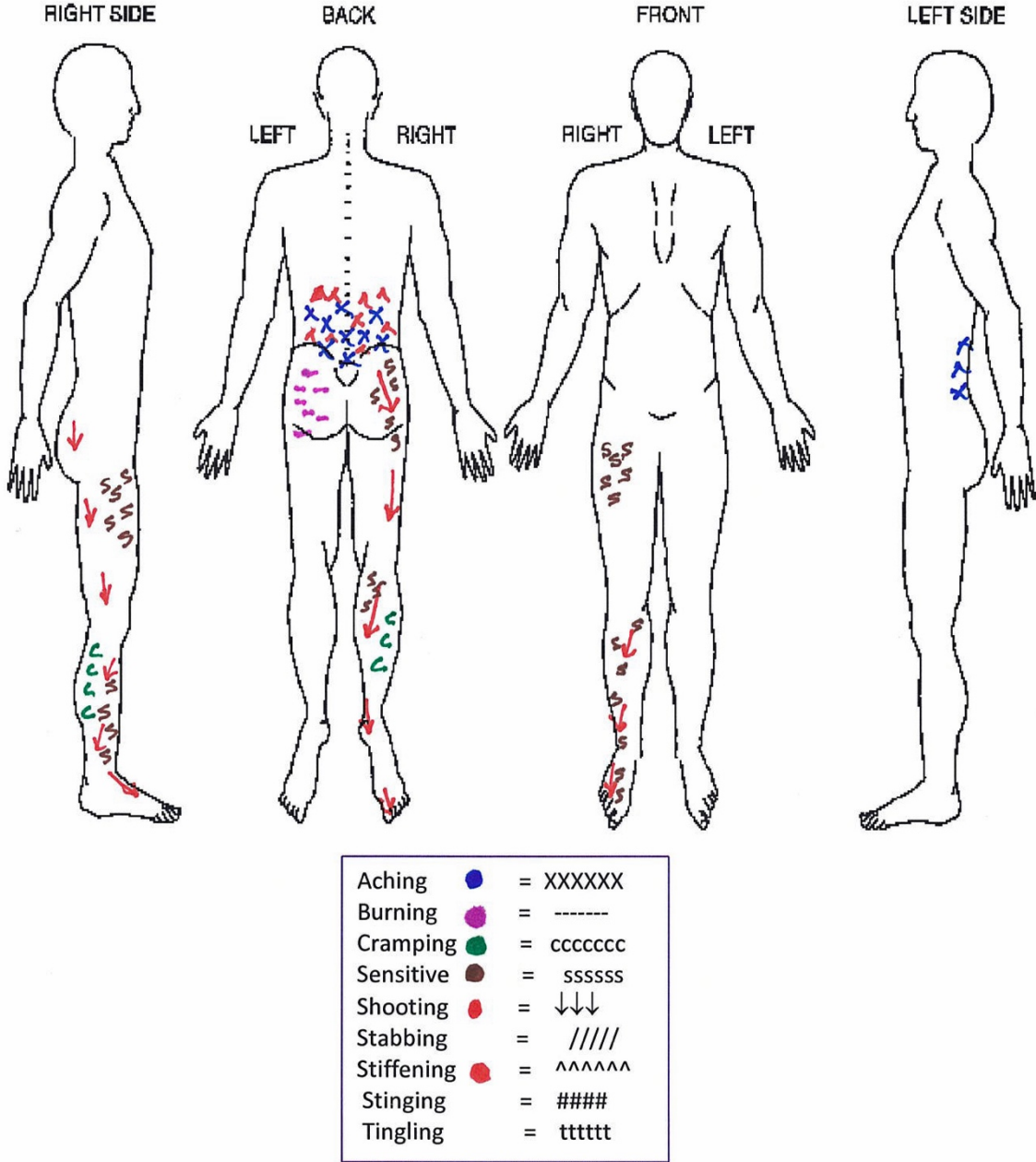
~ ~ ~

The daily pain journal is the way that you capture what your day was like. It is the way that your team sees what each individual day was like.

You can print out as many pages as you need by going to www.globalpaininitiative.org and selecting "Pain Handbook" which will link you to the download for the *Daily Pain Journal*.

Following is an example of a completed **My Pain Diagram** to help you see how it is done:

MY PAIN DIAGRAM



Following is an example of a completed daily pain journal to help you see how it is done.

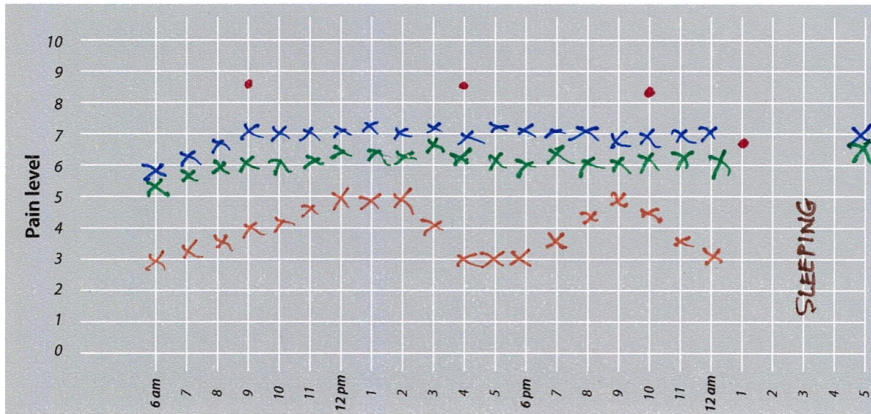
Initial (Day#1) Pain Journal – Page 1

Name: TN
 Day of the week: Tuesday
 Date: 4/8

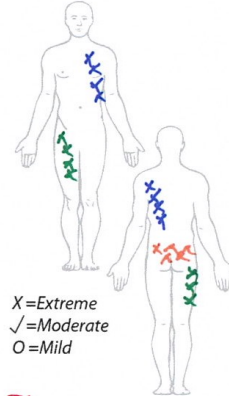
PAGE 1 OF 2

Chest (Blue)
 Thigh (Green)
 Low Back (Orange)
 o = pain flares

1. DAILY PAIN CHART (Connect your points so your team can see your pain variation)



DAILY PAIN DIAGRAM (Mark where you are experiencing pain)



2. PAIN LOG

ACTIVITIES/EXERCISES:	1	2	3	4	← Flares SIDE EFFECTS:
Breakfast	X				
Grocery Store		X → X			
MEDICINE/DOSE:					SIDE EFFECTS:
Ibuprofen 400mg	X	X	X		Upset stomach
Hydrocodone 10/325	X	X	X	X	Constipated
NON-MEDICINE THERAPY:					SIDE EFFECTS:
Heat (lowback)		X → X	X → X		
PROCEDURES:					SIDE EFFECTS:
Radiology		X → X			Really hurt

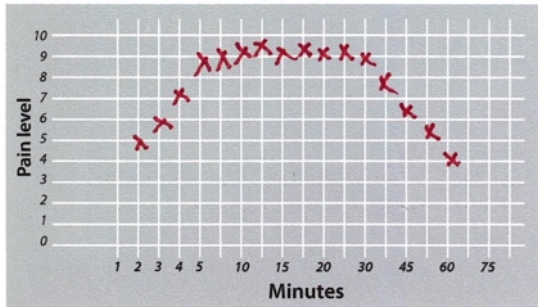
COMMENTS/MORE INFORMATION:

I ache all over for 3-4 days after chemotherapy. When I go to radiology for radiation I really hurt (hard to lay still with my arms up).

PAIN FLARES (use this graph to show how your flares "look")

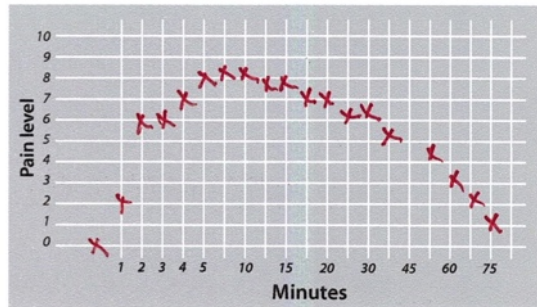
4/8

PAIN FLARE #1: TIME OF DAY: 9:10 AM



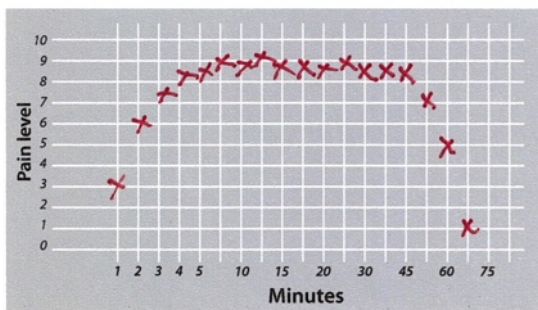
Happened without warning I knew it was going to happen.
I was doing watching TV when it happened.
Medicine/Dose none Did it help?

PAIN FLARE #2: TIME OF DAY: 4:21 PM



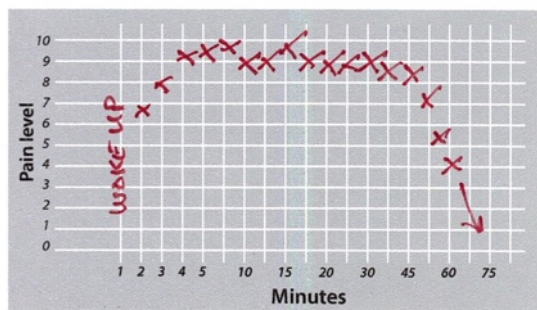
Happened without warning I knew it was going to happen.
I was doing positioning for XRay when it happened.
Medicine/Dose none Did it help?

PAIN FLARE #3: TIME OF DAY: 8:50 PM



Happened without warning I knew it was going to happen.
I was doing reading when it happened.
Medicine/Dose none Did it help?

PAIN FLARE #4: TIME OF DAY: 1:25 AM



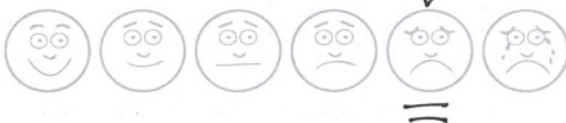
Happened without warning I knew it was going to happen.
I was doing sleeping when it happened.
Medicine/Dose none Did it help?

OTHER FUNCTION (put an 'X' through the one that best represents your day): * after chemo (2-3 days)

Gut: Nausea Vomiting Abnormal Appetite Constipated Diarrhea

Physical: Normal Less None Social: Normal Less None

Mood:



Activity:



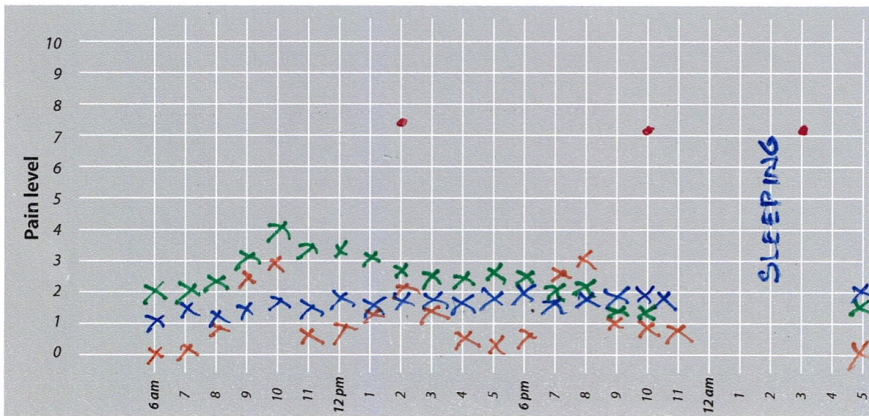
Sleep: All night Moderate Very little None (getting worse)

Alertness: Completely focused Distracted Cannot focus on anything but the pain (when pain gets really bad!)

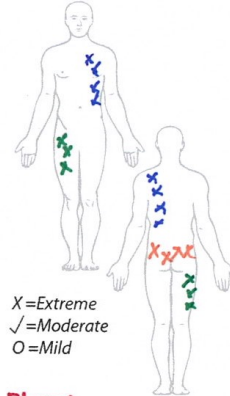
Name: TN
 Day of the week: Saturday
 Date: 5/10

Chest (Blue)
 Thigh (Green)
 Low Back (Orange)

1. DAILY PAIN CHART (Connect your points so your team can see your pain variation)



DAILY PAIN DIAGRAM (Mark where you are experiencing pain)



2. PAIN LOG

ACTIVITIES/EXERCISES:	6 am	7	8	9	10	11	12 pm	1	2	3	4	5	6 pm	7	8	9	10	11	12 am	1	2	3	4	5	SIDE EFFECTS:
Breakfast		X-X																							
Out by Lake							X						X												
Dinner & friends													X		X										
Tv/Read																	X-X								
MEDICINE/DOSE:																									SIDE EFFECTS:
Fentanyl 50	X																								
Hydromorph 4		X		X																					
Fent Spray 400								X						X				X							Works well.
NON-MEDICINE THERAPY:																									SIDE EFFECTS:
TENS		X-X			X								X	X				X							
HEAT			X-X										X-X												} really helps spasms in my back
PROCEDURES:																									SIDE EFFECTS:

COMMENTS/MORE INFORMATION:

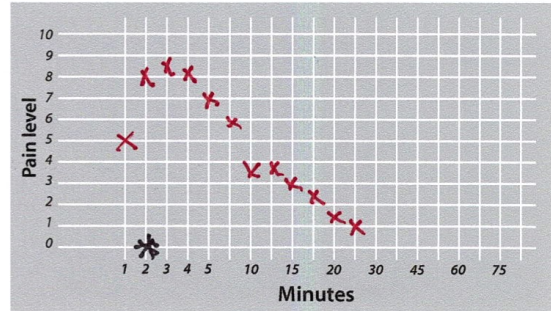
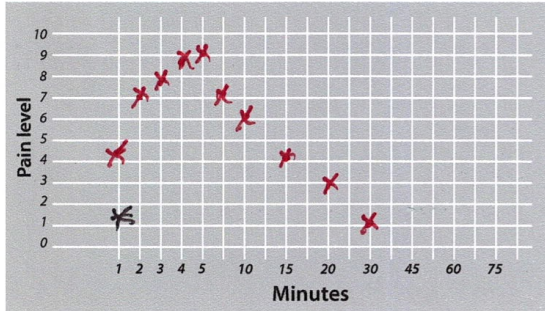
Really active, husband told me I'm much more cheerful

PAIN FLARES (use this graph to show how your flares "look")

5/10

PAIN FLARE #1: TIME OF DAY: 1:40 PM

PAIN FLARE #2: TIME OF DAY: 10:05 PM



Happened without warning ___ I knew it was going to happen.

Happened without warning ___ I knew it was going to happen.

I was doing Sitting by lake when it happened.

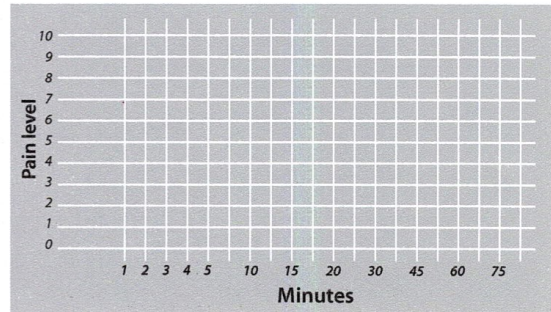
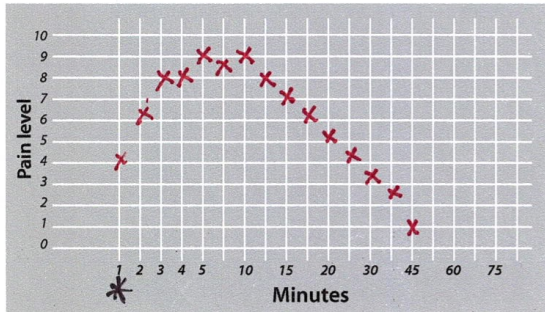
I was doing Reading a book when it happened.

*Medicine/Dose Fentanyl Spray 400 Did it help? Really helped

*Medicine/Dose Fentanyl Spray 400 Did it help? Way!!

PAIN FLARE #3: TIME OF DAY: 3:15 AM

PAIN FLARE #4: TIME OF DAY: _____



Happened without warning ___ I knew it was going to happen.

___ Happened without warning ___ I knew it was going to happen.

I was doing Sleeping when it happened.

I was doing _____ when it happened.

*Medicine/Dose Fentanyl Spray Did it help? Very good

*Medicine/Dose _____ Did it help? _____

OTHER FUNCTION (put an 'X' through the one that best represents your day):

Gut: ___ Nausea ___ Vomiting ___ Abnormal Appetite ___ Constipated ___ Diarrhea OK

Physical: Normal ___ Less ___ None Social: Normal ___ Less ___ None

Mood:

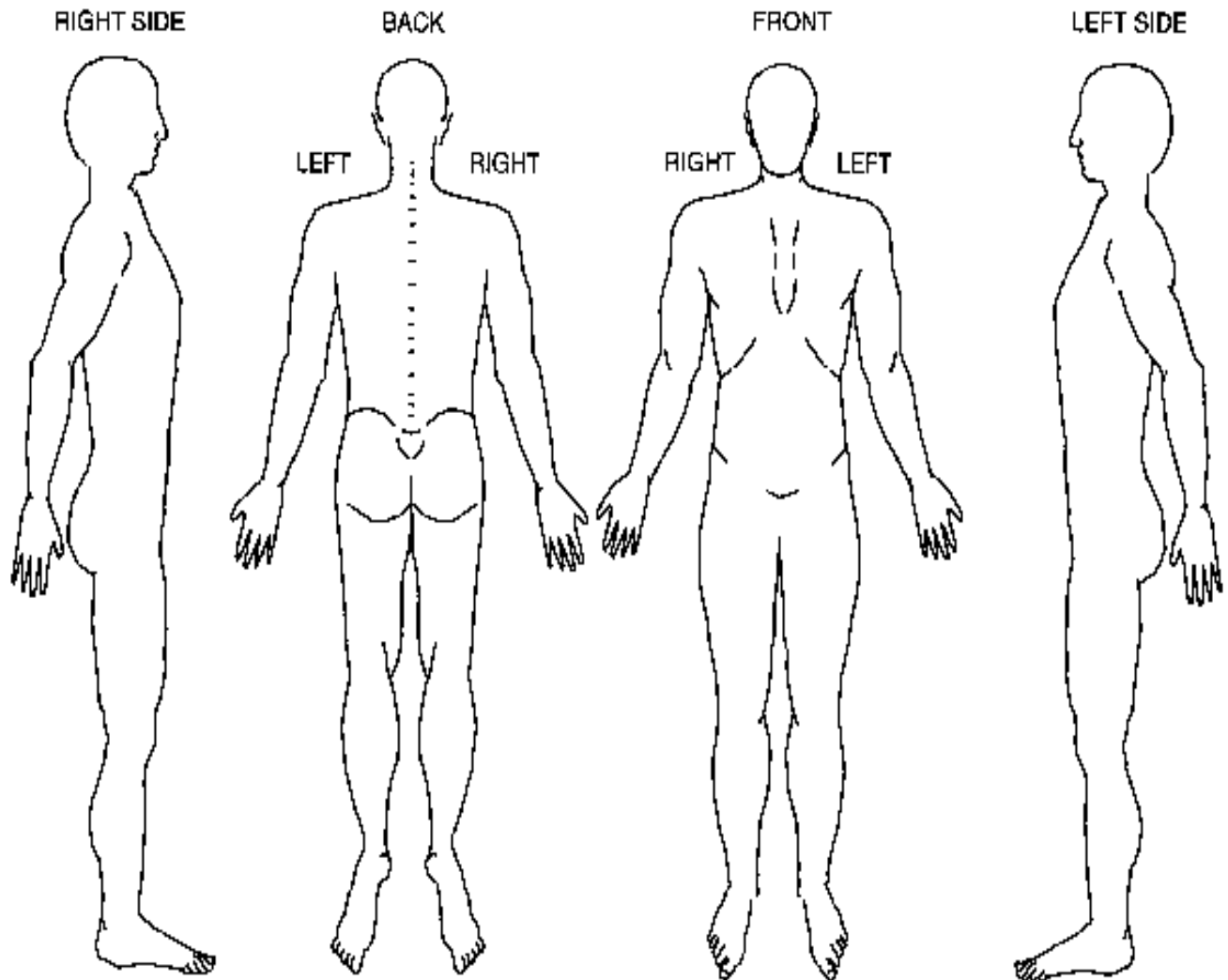
Activity:



Sleep: All night (only lose about 1/2 hr when pain flares!) ___ Moderate ___ Very little ___ None

Alertness: Completely focused ___ Distracted ___ Cannot focus on anything but the pain

MY PAIN DIAGRAM



Aching	=	XXXXXX
Burning	=	-----
Cramping	=	cccccc
Sensitive	=	ssssss
Shooting	=	↓↓↓
Stabbing	=	////
Stiffening	=	^^^^^^
Stinging	=	####
Tingling	=	ttttt

MY CARE TEAM

Team Member	Phone #	Skill, function, or role
My name:		Expert of my own experience with pain
My family doctor:		
My pain specialist:		
My surgeon:		
My _____ specialist:		
My _____ specialist:		
My _____ therapist:		
My _____ therapist:		
My _____ therapist:		
My benefits advisor:		
My case/social worker:		

MY TREATMENT PLAN

MEDICATIONS

NON-MEDICATIONS

PROCEDURES/SURGERIES

**MORE ABOUT PAIN, PAIN TREATMENT,
and PUSHING TOWARD a CURE**

Visit us at:

<http://www.globalpaininitiative.org>