

A Youth Caregiver's Guide to Medication Management

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FOREWORD

Three semesters ago, I took a USF Honors Major Works/Major Issues course on youth caregiving. When we talked about our future goals in life, I made sure to tell my professor, Dr. Donna Cohen, that I wanted to be a pharmacist. Her response was to immediately describe how important the content of this course would be for my future training, because pharmacists and other health care professionals do not recognize the challenges facing youth caregivers. Youth caregivers are children and adolescents under age 18 who sacrifice their education, health and well-being, and leisure of their childhood to provide care for family members of all ages who are sick, injured, or disabled.

The link between the needs of youth caregivers and my dream profession engaged my interest in the course over the entire semester and beyond. The next semester, I contacted Dr. Cohen to discuss my interest in writing a resource manual to help youth caregivers with medication management. She immediately saw this as a wonderful opportunity, because no resources existed for this age group.

Not long into the project, Dr. Cohen suggested I add a committee member-- Dr. Connie Siskowski of Boca Raton, Florida, who is the President and Founder of the American Association of Caregiving Youth (AACY). Dr. Siskowski has been a pioneer as a national advocate for caregiving youth, and she established the country's first Caregiving Youth Project (CYP) based in Palm Beach County middle and high schools. With her expertise and involvement, I not only knew that Dr. Siskowski would be an invaluable resource but also that this workbook would find its way into the hands of youth caregivers who needed the information

Later in my project, Dr. Siskowski introduced me to Cristy Kovach Hom, LCSW, a social worker on the AACY staff. I am also indebted to Cristy for the effort she invested going through chapters with me and offering anecdotes from her experience. I came to understand through Dr. Siskowski and Ms. Hom

how much these young caregivers do, the many challenges they face, and the help they need. Indeed, youth caregivers in every school would benefit from CYP programs and support.

One of the greatest challenges in writing this workbook has been digesting research findings only available for adults and making the material interesting and useful for youth caregivers. Since no resources currently exist for young caregivers, I hope this workbook will be a useful guide. The chapters are intended to provide a wealth of information, including but not limited to:

- Identifying yourself as a person responsible for medications;
- Understanding where to get information and help, including how to ask questions;
- Knowing how to understand the proper storage and organization of medications; and
- Knowing how to recognize a bad reaction to drugs and where to get help.

The accuracy of the chapters has been reviewed by health care professionals. However, it is important to emphasize that this workbook does not replace the advice of doctors and pharmacists.

Finally, I would like to take this opportunity to thank Dr. Cohen, Dr. Siskowski, and Ms. Hom for all their efforts and support in this project. Had someone asked me three semesters ago what I would be writing for my thesis, I would have been flabbergasted about the thesis process and choosing a topic. I cannot express how thankful I am for the direction and support of these women. It feels wonderful to know that something I have written will have an impact on the world.

CHAPTER 1

Introduction

If you are between the ages of 8 and 18, and you are helping to care for a family member who needs to take medications or drugs, this handbook is written for you. YOU are not alone! In the United States, approximately 1.4 million young people your age are caring for a family member who is ill, disabled, or elderly.

If you are in this age group, and you helping take care of a member of your family, you are a very special person. You are a member of an exceptional group of young people known as youth caregivers. You may be young, but you do tasks that many adults do when family members have health problems. This may include all sorts of jobs -- cooking, feeding, dressing, bathing, assistance with walking, calling doctors, housework, shopping, and giving medicines or medications.

About one-third of youth caregivers are helping to give medications. Medications are drugs that help treat medical problems. They may be in the form of pills or capsules taken by mouth, crèmes rubbed on the skin, patches placed on the skin, drops for the nose or ears, liquids taken by the spoonful or through a tube, liquids injected with a needle, or medications inhaled through the nose or mouth.

Giving medications is not a simple task, especially when a person is taking a lot of them. It is easy to make a mistake! Even doctors, nurses and pharmacists with years of training can make mistakes. It is important to know as much as you can about the different medicines you give, so you give them safely.

You need to know the following:

How to organize drugs so you give the right medicine, in the correct amount, in the right way, and at the right times during the day and/or night;

How to store drugs properly;

What to do when problems arise; and

How to ask questions when you need help

If you live with a parent or another adult, ask him or her to help you understand exactly what you need to do. If there is no adult in your home who can help you, please talk to someone about your responsibilities. This may be a guidance counselor or teacher at school as well as an adult relative or neighbor whom you trust. The doctor who takes care of your relative or the pharmacist at the drugstore where you get the medication may also help.

Now, let's start with the basics!

What is a Medication?



A medication is a drug or other substance that is used as a medicine to ease, control, or cure medical conditions. Most medications require prescriptions from a doctor to be filled at a pharmacy or through a mail order pharmacy center. Other medicines can be bought without a prescription. These are known as over-the-counter or OTC medicines.

Not every medical condition requires drug treatments, but drugs can be very effective if prescribed by a knowledgeable and caring doctor.

Many people, especially older people, take a lot of medications. Giving a person many different drugs at different times can be stressful, even for adults! It is possible to become confused or overwhelmed. Giving medication is not a simple process! But, this workbook is intended to help you.



Dosages, Schedules, Food and Drinks—Oh My!



To work effectively and safely, medications have to be given in specific amounts, known as a dose, and at scheduled times. Many medications need to be administered with food, water, or other liquids to work properly.

A doctor makes a judgment when writing a prescription about how much medication – the dosage - a particular person needs. This will depend upon the person's age, weight, sex, and how sick they are. The

dosage will be specified by the number of pills and the strength. If the medication is a liquid, the dosage will be expressed as teaspoons or tablespoons, or cc's (a metric value) that are to be given to the person at a given time.

Giving the prescribed dosage is essential to make sure that the medication will be effective and safe.



Knowing when to give a medication is as important as knowing what the proper dosage is. The doctor or pharmacist should tell you when the medicine is supposed to be given. The label on the pill bottle will tell you how often the medication is supposed to be given and how many hours apart the medicine should be taken.

It is important to know if the medications should be taken with food or water or on an empty stomach. These instructions will be printed on the medicine bottle label. The later chapters will give you tips for reading these labels and keeping track of how much and when medications are given.

Side Effects

Any drug that can help may also hurt. Drugs may have side effects that make a person feel uncomfortable or get sick. Some side effects may be dangerous and cause other health problems. Also, if a person is taking several drugs, it is possible that these drugs may interact with each other. In addition, some drugs may interact with certain foods and cause undesired effects.

When doctors prescribe a medication, they take into account other medications a person is taking and how the person has reacted to drugs in the past. Doctors often start a person on a small amount of a drug and increase it slowly. This is a good way to reduce the chance of major side effects.

It is important to understand what a side effect is and know who can help and how to ask for help. Different medications have different side effects. Some examples of side effects include rashes, frequent headaches, stomach aches, tiredness and weakness. An example of a major side effect is that the ability to breathe can be blocked.

When the prescription is filled by a pharmacist, a piece of paper with a description of the medication and its side effects is included in the packaging or given when the medicine is picked up or delivered.

It is important to know who can help you and what to do when you recognize that a possible side effect is occurring. Call 911 if the person is in great distress—such as having breathing problems, feeling dizzy, not responsive to you. If you think this is an emergency, call 911 for help. You can also then call a parent who may be at work or a nearby neighbor.

It is a good idea to make a plan when you begin giving medication about who you should contact in an emergency.

Questions You May Have

It is important to use the knowledge you learn in your caregiving role to ask questions. It is essential that you know who the proper person is to ask questions in different situations. Do not ever hesitate to ask an adult or a healthcare professional for help when you are confused or not sure of what to do.

Remember, there are situations where calling for help might save the life of the people for whom you provide care.

References

If you are interested about learning about different health conditions and diseases or you want to know more about medications, go to the websites listed here:

http://kidshealth.org/kid/health_problems/index.html

This link has good information about health and diseases.

http://kidshealth.org/kid/feel_better/things/kidmedic.html

This link explains medicine in an understandable way.

Self-Quiz

The goal of this self-quiz is to help you think about the various medications your family member is taking. You may also realize that you know more than you think you do! Answer the following questions and use the answers as a reference in the future.

1. In the table below write the diseases and the medication your loved one takes for the disease in the columns. You may have to ask somebody for help.

Disease	Medication for the Disease	Medication for the Disease

2. How do you feel when you give medications? Do you feel confident? Afraid? Wish you knew more?

CHAPTER 2

One Label at a Time

In this chapter, you will learn what is on a prescription label. With this knowledge, you can then understand:

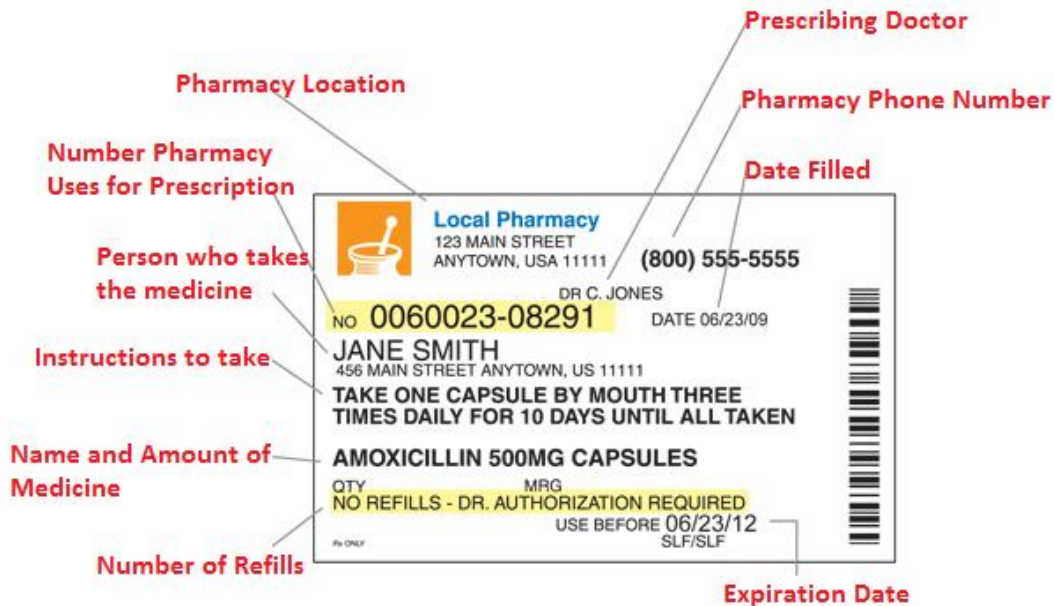
- The right number of pills or amount of a liquid to be given
- How often the medication is needed
- Whether you need to give the medication with food or water
- Instructions for storing bottles or containers

Always begin by reading the label!

The label on any pill bottle, medication container, or medication package gives you a lot of information about the medication. However, learning what it all means can be tricky. But, it doesn't have to be! So, let's look at it one part at a time!

Typical Prescription Labels

Below is a picture of a typical prescription label with text to help you understand the different types of information:



The address and phone number for the pharmacy are on the label as well as the name of the doctor who prescribed the medication. You can find the date the medication was filled and the “use before” or expiration date of the medication.

It is important to know when someone started taking a medication as well as when the medicine expires. When medicines get old, they do not work as well, and sometimes they may cause harm. Do not keep or use medications after their expiration date!

The doctor may specify the number of times you can get a refill when the medicine in one container runs out. If there are refills left, you can go to the pharmacy and get another bottle of the medicine. Call ahead of time so the medication is ready for you to pick up. If no refills left, contact the doctor for another prescription, if the medication is still needed.

The only person who should get a certain medicine is the person whose name is on the label. Unless the medication is one that does not need a prescription, such as Tylenol or Aspirin, never give your relative a pill from a bottle when his or her name is not on the label. This may seem obvious, but sometimes people will borrow medicine from friends to save money.

Labels provide information about the name of the medication, how much medicine should be taken at one time (how many pills, ccs or spoonfuls) and how often the medicine should be taken.

Sometimes common side effects and more serious side effects are printed on the label. These side effects are reactions that may occur when taking the medicine. (This will be discussed in Chapter 4). The special instructions usually refer to the importance of taking the medicine with food or water so the medication works the way it should.



Over-The-Counter (OTC) Labels

Drug Facts

Active ingredient (in each tablet)	Purpose
Chlorpheniramine maleate 2 mg	Antihistamine

Uses temporarily relieves these symptoms due to hay fever or other upper respiratory allergies:
 ■ sneezing ■ runny nose ■ itchy, watery eyes
 ■ itchy throat

Warnings
Ask a doctor before use if you have
 ■ glaucoma
 ■ a breathing problem such as emphysema or chronic bronchitis
 ■ trouble urinating due to an enlarged prostate gland

Ask a doctor or pharmacist before use if you are taking tranquilizers or sedatives

When using this product
 ■ You may get drowsy ■ Avoid alcoholic drinks
 ■ Alcohol, sedatives, and tranquilizers may increase drowsiness
 ■ Be careful when driving a motor vehicle or operating machinery
 ■ Excitability may occur, especially in children

If pregnant or breastfeeding, ask a health professional before use.
Keep out of reach of children. In case of overdose, get medical help or contact a Poison Control Center right away.

Directions

Adults and children 12 years and over	Take 2 tablets every 4 to 6 hours; not more than 12 tablets in 24 hours.
Children 6 years to under 12 years	Take 1 tablet every 4 to 6 hours; not more than 6 tablets in 24 hours.
Children under 6 years	Ask a doctor

Other information Store at 20-25° C (68-77° F)
 ■ Protect from excessive moisture

Inactive ingredients D&C yellow no. 10, lactose, magnesium stearate, microcrystalline cellulose, pregelatinized starch

Over-the-counter (OTC) medicines can be obtained without a prescription from a doctor. They can be bought at a drugstore or grocery store. However, they still have a label with important information printed on them.

Use the picture as a guide to understand how to read an OTC medicine label.

The most important part of an OTC label is the warning section that tells you when someone should not take the medicine. It is best to contact a doctor before using the medicine if your relative has any of the conditions listed.

The label indicates what symptoms or conditions the medicine is intended to help treat, side effects of the medicine, the recommended amount of medicine to be taken, and how often it should be taken during the day. It also gives storage information.

It is just as important to be aware of the information on OTC medicines as it is for prescription medicines. Your family member's primary doctor should also know what OTC medications are being taken.

Importance of Dosages and Special Instructions

The first chapter of this workbook introduced you to the importance of dosages and following instructions when giving medications. Now you know where to find information about dosages and instructions on medication labels.

It is important to give the exact amount that the label calls for, because this is the amount of medicine that will work the best for your relative. Taking too much medicine is just as bad as not taking enough. If you are unsure what a tablespoon or a teaspoon is, ask someone so that you give the right

amount. It is important to give the right dosage at the right time. Certain medicines will stay in the body for different amounts of time. Giving them too close together may cause side effects, and giving them too far apart will decrease how well they work.

The special storage instructions on medicine labels are important so that the medicine stays effective. When a medicine is placed in an environment that is too cool, warm or moist, will make it work less well. Moisture or temperature will affect the chemicals of the medicine, and they will not work properly in the body.

Finally, when a label says a medicine needs to be taken with food or drink, follow these directions. Usually the drink or food helps the stomach begin to break down the medicine so it can get into the rest of the body. Sometimes medicines can be really strong and hurt the inside of the stomach without food there to help.

Questions

If you have questions after reading this chapter, it is important to talk with an appropriate healthcare professional, such as a pharmacist, doctor or nurse.

Reading a prescription label can be difficult so it is especially important to ask questions if you do not understand the information. If a nurse or adult who can read and understand the label is around, ask them to review the label with you. Since the phone number for the pharmacy is written on the label, you can always call the pharmacy and ask them a question about the medicine.

Some of these questions may include:

The label for this medication says, “give 2 pills, 3 times daily.” Does that mean I give my loved one 2 pills in the morning, 2 in the afternoon, and 2 before bed?

If I do not have a measuring spoon in my house, what can I use instead for a tablespoon or teaspoon?

The label says to store the medicine in the refrigerator. If I accidentally leave it out for a few hours on the counter, what will happen?

No question is a stupid question. Just remember to always ask an adult for help instead of staying silent.

Self-Quiz

What is the importance of giving the right dosage at the right time, knowing to give water or food with the medication, and storing the medication properly?

Fill in the blanks of this label to tell what each line is pointing to:

The image shows a medication label for Amoxicillin 500mg Capsules. The label contains the following text:

Local Pharmacy
123 MAIN STREET
ANYTOWN, USA 11111 (800) 555-5555

DR. C. JONES
DATE 06/23/09

NO 0060023-08291

JANE SMITH
456 MAIN STREET ANYTOWN, US 11111

TAKE ONE CAPSULE BY MOUTH THREE TIMES DAILY FOR 10 DAYS UNTIL ALL TAKEN

AMOXICILLIN 500MG CAPSULES

QTY MRG
NO REFILLS - DR. AUTHORIZATION REQUIRED
USE BEFORE 06/23/12
SLF/SLF

PH ONLY

There are ten numbered boxes with lines pointing to specific parts of the label:

- 1. Points to the pharmacy logo.
- 2. Points to the pharmacy name and address.
- 3. Points to the patient name and address.
- 4. Points to the dosage instructions.
- 5. Points to the medication name.
- 6. Points to the quantity and refill information.
- 7. Points to the pharmacist's name and date.
- 8. Points to the pharmacy phone number.
- 9. Points to the prescription number.
- 10. Points to the barcode.

Use the pictures to answer the questions below them:

1

DVB Pharmacy #0011 ph. 718 555-1144
121 Hillside Avenue
Jamaica, NY 11432
DEA #DVB1234510

Rx: 04444

LAMICTAL 100 mg Tab

PRESCRIBER: CASE, DAVID V

Take 1 and ½ Tablets Every Morning & at 6pm.

No Refills Qty: 270

RPh: TORETTA, GREGORY
Filed: 04-05-2006 Rx Written: 02-02-2006 Do Not Use After: 04-05-2007

AISE BAYKAL
15-02 Main St
Flushing, NY 11367

2

CSV/pharmacy #0201 ph. 518-567-4321
1191 Madison Avenue, Schenectady NY 12305 DEA #DVB1234510

Rx#053570278812

Welchol 625 mg Tab

Dr: Nordlicht, k
Date: 01/23/06

Take 2 Tablets 3 Times a Day

REFILLS: 3 Qty: 90 Reorder after 05-16-2006

RPh: B. Cesnak Filed: 03-27-2006 Do Not Use After: 03-02-2008

CAUTION: FEDERAL LAW PROHIBITS TRANSFER OF THIS DRUG TO ANY PERSON OTHER THAN THE PATIENT FOR WHOM IT WAS PRESCRIBED.

Kim, Eun-Hee
125-02 Kissena Blvd
Flushing, NY 11367

What is the name of the medicine?

What is the doctor's name?

What is the patient's name?

What is the pharmacy's phone number?

How many pills do you take every day?

How many pills are in the bottle?

Can you get a refill?

When does the medicine expire?

What is the name of the medicine?

What is the doctor's name?

What is the patient's name?

What is the pharmacy's phone number?

How many pills do you take every day?

How many pills are in the bottle?

Can you get a refill?

When does the medicine expire?

Answers:

Fill in the Blank

- | | |
|--|-----------------------|
| 1. Pharmacy Location | 6. Number of Refills |
| 2. Number Pharmacy uses for Prescription | 7. Prescribing Doctor |
| 3. Person who takes medicine | 8. Pharmacy Number |
| 4. Instructions to take | 9. Date Filled |
| 5. Name and Amount of Medicine | 10. Expiration Date |

Pictures and Questions

1.

What is the name of the medicine? Lamictal
What is the doctor's name? David C. Case
What is the patient's name? Aise Baykal
What is the pharmacy's phone number? 718-555-1144
How many pills do you take every day? 3
How many pills are in the bottle? 270
Can you get a refill? No
When does the medicine expire? 4/05/2007

2.

What is the name of the medicine? Wenchol
What is the doctor's name? Dr. K. Nordlicht
What is the patient's name? Kim Eun-Hee
What is the pharmacy's phone number? 518-567-4321
How many pills do you take every day? 6
How many pills are in the bottle? 90
Can you get a refill? Yes, 3.
When does the medicine expire? 3/02/2008

CHAPTER 3

So Many Pills--Where do I begin?

Many people, especially older people, are taking many different medications. This means that it is important to organize all of these different medications so you can give them at the right time and in the right dose. This chapter will explain ways you can organize the different medications and keep track of what you are doing.

The Usefulness of Lists

Make a list of all current medications your family member is taking and add information that is written on the medication label. Keep this in the room where you store the medication—usually the kitchen or a bedroom. You may post it on a bulletin board, place it on the refrigerator door under a magnet, or keep it in the same drawer or place where you store the medications. When your relative visits the doctor, take the list with you and ask questions to understand the different medications.

If you have a computer, using a program like Microsoft Excel or Microsoft Word can be handy for creating tables. You can title the different columns or rows with information that is important. You can always draw tables with paper and pencil too. The following table is an example of a good way to keep a list of medicine and the important information about it:

Current Medication List of _____						
<i>Use this list to keep a record and also bring it to each doctor's office or other place of seeking medical help including the Emergency Room</i>						
Medicine	Dose	Doctor who Prescribed it	Date it was prescribed	Color, shape and size of medicine	What it is for?	Time to Give Medication
1.						
2.						
3.						

The Importance of Being Organized

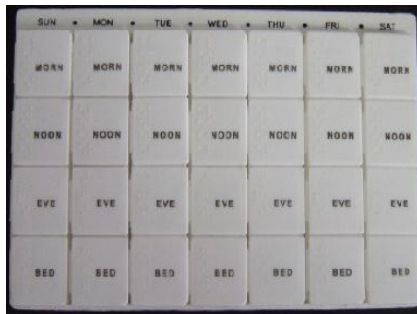
Having a list of medications is the first step to being organized. Second, it is important to know where medications are stored-- in a cabinet, the refrigerator, or pill box, because being organized can help prevent you from making mistakes when giving medications. You need to give the right medication, at the proper dose and at the correct time.

There are several helpful ways to organize medications.

1. You can create a color system for the labels, where different colors stand for different days or times. For example, if the person you care for has to take a certain medication in the morning, you could put a blue sticker on it. If that same medication also needs taken at night, you could put both a blue and red sticker on it. However, you need to keep a checklist with the color codes on them so you know which colors you assigned to what times.

2. Using a pill box is probably the best way to organize medications. You can buy these at any drugstore. A pill box holds medication and is labeled with the times of the day and days of the week. Each medication can be placed in a spot to be given at the right times. There are many different types of pill boxes. Ask your pharmacist to help you select the best type of pill box for your needs,

Below are pictures of several types of pill boxes:



The picture above is a more advanced pill box with places to put medicine every day of the week with their given times of the day



The picture above is a simple pill box with places to put medicine for the morning and bedtime each day of the week.



The picture to the left is an advanced electronic pill box. They can be set with alarm reminders of when to give medications on different days.

Getting into the routine of organizing medication with the help of pillboxes or color labels can make managing medication easier and safer. Today, there are even more advanced electronic medication aids that open automatically and remind your family member to take the medication when you are not at home.

Schedules

Schedules are important for remembering what needs to be taken and when. A schedule for school tells you what classes you are taking and what time they are. The same is true for medications. A schedule tells you when to give a pill or other medicine. A pill box (as shown above) makes schedule-making an easy task once the medicines are in boxes for the right days and times.

Once again, it can be helpful to use computer programs like Microsoft Word or Excel to make tables. It may also be easier to use a pen or pencil to draw a schedule on a piece of paper.

Below is a sample blank schedule where you can write medicine names and the appropriate times and days they need to be given:

Making a Schedule							
Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning							
Noon							
Evening							
Bed-Time							
During the night							

You should use this schedule if you are responsible for placing the medicines in the pill box.

As you can see, creating a schedule can be very helpful. Schedules and lists can also be useful when going to the doctor to ask questions about the different medicines that you have written down. Being organized is a good way to keep track of what you are doing and lets you give medications safely.

Questions

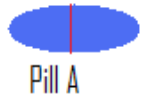
Ask for help if you are confused about how to keep medications organized. You can ask home health nurses or another adult to help you do this. It may also be useful to ask the pharmacist if they have suggestions for how to organize medications. They may show you a useful pill box on a shelf in the store that you can use.

If you lose track of a dosage of pills, never assume you did or did not give the pill. Ask an adult to help you figure out if you may have lost a pill or skipped a dose. It may be safer to skip the dose than accidentally give twice as many pills at a given time. You can call a pharmacist or doctor to ask about this.

You should never do something you feel uncomfortable with and should always ask questions or get help immediately.

Self-Quiz

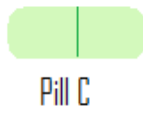
- Below is an example of 3 different pills and the instructions given with them. Use the picture of the partial pill box to draw the number of each pill you would place in the given day and time slots.



To be given 2 times a day; Once in the Morning and Once before Bed.
Give 2 Pills as each dosage.



To be given ONCE a day at Noon. Take 1 Pill as the dosage.



To be given 2 times a day; Once at Noon and Once In the Evening.
Take 2 Pills as each dosage.

	Monday	Tuesday
Morning		
Noon		
Evening		
Before Bed		

2. Why can having a schedule or list of medications be helpful for making medication giving safer and easier?

Answers:

1. Monday and Tuesday have the same pills.

Morning: 2 Pill As—Drawing two blue pills would be correct.

Noon: 1 Pill B, 2 Pill Cs—Drawing 1 yellow pill and 2 green pills would be correct.

Evening: 2 Pill Cs—Drawing 2 green pills would be correct.

Before Bed: 2 Pill As—Drawing two blue pills would be correct.

Feel free to cut or pull out these pages to write on and have copies of the medication list and schedule.

Current Medication List of _____						
<i>Use this list to keep a record and also bring it to each doctor's office or other place of seeking medical help including the Emergency Room</i>						
Medicine	Dose	Doctor who Prescribed it	Date it was prescribed	Color, shape and size of medicine	What it is for?	Time to Give Medication
1.						
2.						
3.						
4.						
5.						

Making a Schedule							
Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning							
Noon							
Evening							
Bed-Time							
During the night							

CHAPTER 4

An Aside about Side Effects

Although medicines are taken to treat a specific problem, such as aspirin or ibuprofen for headaches or insulin for diabetes, they can also have what are known as side effects. Side effects refer to reactions some people may have to taking the medicine. Side effects can make a person feel uncomfortable or put him or her at risk for serious health problems.

The chart below gives examples of some of the types of side effects you may find printed on medicine labels or inserts. These side effects – serious ones and less serious ones—depend on a number of factors.

Serious side effects include: <ul style="list-style-type: none">• heart attack• stroke• high blood pressure• heart failure from body swelling (fluid retention)• kidney problems including kidney failure• bleeding and ulcers in the stomach and intestine• low red blood cells (anemia)• life-threatening skin reactions• life-threatening allergic reactions• liver problems including liver failure• asthma attacks in people who have asthma	Other side effects include: <ul style="list-style-type: none">• stomach pain• constipation• diarrhea• gas• heartburn• nausea• vomiting• dizziness
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<http://dailymed.nlm.nih.gov/dailymed/drugInfo.cfm?id=59874>

It is not possible to predict if a person will experience side effects to a certain medication. For this reason, it is very important to know what side effects could possibly occur and watch for them.

Many people do not experience any side effects. However, it is essential to know what side effects might occur so you can be prepared to call a doctor.

More about Side Effects

All medicines on the market have been tested for their safety and approved by a government organization called the Federal Drug Administration, or the FDA. The FDA reviews all the studies done on a medicine. This includes the types of side effects and the number of people who have experienced them. For a medicine to be approved, the number of people who experience serious side effects must be very low.

The side effects printed on the medication label are ones that were seen when the medicine was being tested in studies with large numbers of people.



Certain medications do not react well with other ones, and these problems are known as drug interactions. Most of the time, pharmacists and doctors are aware of these drug interactions and do not prescribe drugs that would have bad effects when taken together.

The possibilities of side effects or drug-drug interactions are reasons that it is important to take a list of medications when your relative goes to see their doctor. Ask the doctor to review all the medications for possible bad effects. For example, some medications may raise blood pressure, and this would not be good if a person is being treated for high blood pressure.



Medications Need to Be Taken on Time

Reactions can also occur when people forget to take their medication too many times or refuse to take their medication. For many medications, it is possible to miss a dose, but the longer a person refuses a medication, the greater the risk for a health problem or crisis. Contact a health care professional or an adult you trust if your relative is not taking his or her medication.

Medication Withdrawal

Some medications cannot be stopped suddenly without causing serious problems. This is the case with medical problems such as asthma, diabetes, heart diseases, depression, and epilepsy. However, this is not a complete list of health problems.

When a doctor prescribes a medication, a person needs to take it until the doctor says it is no longer necessary. For the health problems listed above, a person will usually stay on medications for a long time, if not their entire life.

It is common, however, for a doctor to change a medication for one that works better or has fewer side effects. In these situations, the doctor will want to lower the dose slowly so that a person's body adapts to the changes without bad effects.

The important message here is that you should always follow the doctor's prescriptions for drugs and never stop taking medication suddenly for any reason. Only the doctor can make the decision that it is okay for someone to stop taking medications.

References

<http://www.drugs.com/sfx/>

The above website lets you type in a medication and then provides information about the potential side effects. This can be handy if you want to do some research about your relative's medications.

<http://reference.medscape.com/drug-interactionchecker>

This website is useful for learning about the drug interactions of different medications. You simply type in a list of all the medications your relative is taking and any potential interactions are highlighted. You can also use this as a tool to ask the doctor or pharmacist questions about the safety of these drugs.

Self-Quiz

Below are two stories related to side effects. Given the material you have just read, think about what would be the best response in each situation.

1. You are the primary caregiver for your mother who takes a lot of medications for diabetes and pain. You suspect your mother is taking more pain pills than she should be because the number of pills in the bottle seems smaller than it should be.

When you ask your mother about this, she gets upset and argues with you. She then disappears into her bedroom. When you check on her, you find the pain medication bottle open and realize she may have taken them. She is unconscious on her bed.

What is the first thing you should do in this situation? Why?

- A. Use the telephone to call 9-1-1
- B. Call a family member
- C. Call your neighbor
- D. Assume she is just sleeping and let it wear off

2. You are the caregiver for your father who takes a lot of different medications. One of them is an antidepressant, which your father thinks is very expensive. He tells you that he does not need the medicine anymore, and as soon as the prescription runs out, he is going to stop taking it.

You do not think this is a good idea. Who do you suggest that your father talk to?

- A. The neighbor, because she or he might be able to talk some sense into your dad
- B. Your grandma, because she knows how to tell your dad when he is doing something wrong
- C. The doctor, because you suspect stopping the antidepressants could cause serious problems

If your father will not talk to anyone, what should you do?

Answers:

1. A. The fact that your mother is unconscious and may have taken too many painkillers is an indication of an overdose. In this case, you should call 9-1-1 immediately. Afterwards, call the others.
2. C. Although calling the neighbor or grandmother may help, it is only a temporary solution to the problem. The real issue is for your father to talk to his doctor about treatment for his depression.

If your father refuses to talk to anybody, your best option is to contact someone in your family you trust or the doctor and explain the situation to them. If you are concerned about your father's health and can explain the situation to an adult or healthcare professional, they can help you develop a plan for what to do.

CHAPTER 5

Apply Your Knowledge

This chapter presents several real life situations that have happened to other youth caregivers. Read each case and think about whom you would get help from and how you would handle the situation. Questions follow the stories to help you think about what you would do.

Situation 1: Picking Up Medication from the Pharmacy

You are the primary caregiver for your mother. She cannot make it to the pharmacy today and asks you to pick up the prescription for her. You know that this medication, called methadone, is a really strong pain reliever, and you feel uncomfortable doing this.

When you get to the pharmacy, you explain the situation to the pharmacist. He gives you your mother's methadone, because he has known you and your mother for a long time. He also tells you that their usual policy is not to allow a person under the age of 18 to pick up medications like methadone.

When you get home, you tell your mother that you feel uncomfortable picking up this medication for her. She asks you if you can continue getting it for her since you have already done so. You really do not want to do this, but she doesn't seem to listen to you.

You want to talk to someone this situation. Who do you talk to and what do you say? (You can choose more than one answer).

- A. A close relative
- B. A youth caregiving program staff member
- C. The doctor
- D. The pharmacist

Situation 2: Asking Questions

You are in the sixth grade, and you are taking care of your father who has a disease called multiple sclerosis. This disease affects his vision and speech, his ability to move around, and his ability to go the bathroom. It also affects his ability to remember things.

You live alone with your father, and you have taken it upon yourself to manage his medications and injections. Giving the medication is a lot of work, and sometimes you feel like you are not giving the medications properly. You are very anxious because you want to be sure that you are doing everything the right way.

A nurse comes to the house three times a week to help your father. You think that she can teach you more about giving medications. What kinds of questions could you ask the nurse?

Situation 3: Feeling Overwhelmed

You are a senior in high school. Your mother, who has had diabetes for many years, recently had a stroke. You are in charge of giving her all her medications, including her insulin shots.

The pressures of your school work and your need to manage your mother’s medications have you feeling very stressed and upset. Even though you have everything organized, the anxiety and fear of missing a dose or doing it wrong is overwhelming. Who do you ask for help and what do you tell them?

- A. A close relative
- B. The doctor
- C. The pharmacist
- D. A youth caregiving program staff member

Situation 4: Teaching a Friend

You have a friend at school who is in the same caregiving situation as you are. You have been helping your mother take her medications for years and feel confident about how to manage them.

Your friend is fairly new to caregiving and explains his worries about giving medications. He tells you his mother takes four different pills at various times, and he is worried that someday he will forget one of them.

You have been using a labeling and scheduling system for medications. How would you describe your system to your friend? What specific suggestions or advice would you give him?

Concluding Ideas

A workbook cannot describe every situation that may confront you as a youth caregiver giving medications. The few examples in this chapter will hopefully be helpful and encourage you to ask questions and get help.

Getting help when you don't know what to do or when you are feeling anxious and stressed is one of the most important principles of caregiving.

Answers:

Situation 1: Picking Up Certain Medications at the Pharmacy

A or B

The main goal is to tell someone you are uncomfortable about picking up this medication.

The role of a doctor or pharmacist is to give you information about the medication.

Answer A, a close relative, can be especially useful. You could ask them if they would be willing to talk with your mother about picking up the medication.

Answer B, a youth caregiving staff member, is certainly the right choice if you are in a caregiver support program. These trained specialists can help you feel more comfortable with the situation or find a way to get you the help you need.

The best way to talk to adults is to explain the situation, let them know how uncomfortable you feel and ask them to help you. Starting the conversation is the first step to getting help.

Situation 2: Asking Questions

If a nurse is coming to the house several times a week, ask her to share her knowledge of medication management with you. Do not be afraid to ask her to go over the entire process – how to read the label, how to know what dose to give and when to give it, how to organize the pills or liquid medications, what side effects to look for, and what to do if you think there is a problem.

Many of these questions may come from previous chapters in this book. Even if you have read these chapters, you may still have questions. Do not be afraid. Asking questions is the right thing to do! Not asking is the wrong thing to do!

Having a nurse show you how to manage medication properly can help to relieve your stress .

Situation 3: Feeling Overwhelmed

A or D

The main concerns in this situation may be your lack of confidence and need for reassurance that you are doing everything correctly. Depending on how overwhelmed you feel, you may need someone to take over your tasks for a while and give you a break. This is not an admission that you cannot do the job. Instead, having a brief break is good for you. This gives you some relief from your stress, and then you can go back to your job feeling better.

The doctor or pharmacist can tell you what could go wrong if you miss a dose or make a mistake. However, they can't come into your household and take over your responsibilities.

A close relative or adult you trust may be able to do this for you. A youth caregiving program staff member can help you reduce your anxiety and increase your confidence. They may also be able to help you find someone else to give the medications to your family member.

When talking to adults, let them know how overwhelmed you feel. Talk about the pressures of juggling your school work, and caregiving responsibilities. It is normal to feel overwhelmed and anxious. Most of the time, it means that you care.

Asking for help is what you need to do to get a conversation started.

Situation 4: Teaching a Friend

Give your friend a copy of this workbook or find time to sit down together to go over the material with them, chapter by chapter. You may be the best teacher there is because you know the challenges of helping a family member with their medication. You also know how good it feels to be able to help your family member.

References

- Centers for Disease Control and Prevention. "The State of Aging and Health in America." 2004. *CDC.gov*. PDF. 12 November 2012.
<http://www.cdc.gov/aging/pdf/State_of_Aging_and_Health_in_America_2004.pdf>.
- Centers for Medicare and Medicaid Services. "Your Guide to Medicare Prescription Drug Coverage." November 2009. <http://www.medicare.gov/publications/pubs/pdf/11109.pdf>. PDF. 20 April 2012.
- De Maria, C, M Lussier and J Bajcar. "What do children know about medications?" *Canadian Family Physician* 57.3 (2011): 291-295. PDF. 2012.
<<http://www.cfp.ca/content/57/3/291.full.pdf+html>>.
- Hunt, G, C Levine and L Naiditch. *Young Caregivers in the US: Report of Findings*. Bethesda, MD: National Alliance for Caregiving and United Hospital Fund, 2005. PDF. November 2011.
<<http://www.caregiving.org/data/youngcaregivers.pdf>>.
- Joseph, S, F Becker and S Becker. *Manual for Measures of Caring Activities and Outcomes for Children and Young People*. London: The Princess Royal Trust for Carers, 2009. PDF.
<<http://www.youngcarers.net.au/system/files/Manual%20for%20Measures%20of%20Caring%20Activities%20and%20Outcomes%20for%20children%20and%20young%20people.pdf>>.
- Kain, Carole. "Young Caregivers: They're Just Muddling Through." *Florida Association of School Nurses*. Orlando, FL, 2010. Powerpoint PDF. November 2011.
<<http://www.fasn.net/documents/conference/Young%20Caregivers.pdf>>.
- Letizia, M, S Creech and E Norton . "Barriers to Caregiver Administration of Pain Medication in Hospice Care." *Journal of Pain and Symptom Management* 27.2 (February 2004): 114-24. PDF. 2012.
<<http://download.journals.elsevierhealth.com/pdfs/journals/0885-3924/PIIS0885392403005104.pdf>>.
- National Alliance for Caregiving and AARP. "Caregivers of Younger Adults: A focused look at those caring for someone age 18 to 49." 2009. *National Alliance for Caregiving*. PDF. November 2011.
<http://www.caregiving.org/data/Report_Caregivers_of_Younger_Adults_11-12-09.pdf>.
- National Pain Foundation, Inc. *Giving Medications*. March 2008.
<http://www.nationalpainfoundation.org/articles/263/giving-medications>. 8 September 2011.
- Rabow, M, J Hauser and J Adams. "Supporting Family Caregivers at the End of Life." *Journal of the American Medical Association* 291.4 (Jan 2004): 483-91. PDF.
<<http://www.commed.vcu.edu/IntroPH/Aging/familycaregiversandmd.pdf>>.

Reinhard, S, et al. "Chapter 14: Supporting Family Caregivers in Providing Care." *Patient Safety and Quality: An Evidence-Based Handbook for Nurses: Vol. 1*. Rockville, April 2008. 341-402. PDF. <<http://www.ncbi.nlm.nih.gov/books/NBK2665/pdf/ch14.pdf>>.

Stern, Debbie. "The Littlest Caregivers." *Lynn Magazine* Winter 2010: 19-21. PDF. 8 October 2011. <<http://magazine.lynn.edu/wp-content/uploads/PDF/Magazine-Winter-2010.>>.

Travis, S, L Bethea and P Winn. "Medication administration hassles reported by family caregivers." *Journal of Gerontology* (2000): 412-17. PDF. 2012. <<http://www.biomedgerontology.oxfordjournals.org>>.

US National Library of Medicine. *How to Write Easy-to-read Health Materials*. April 2011. 24 April 2012. <<http://www.nlm.nih.gov/medlineplus/etr.html>>.

Viola, D, et al. "Family Carers in the US." *International Conference on Evidence-based Policy in Long Term Care*. London: London School of Economics, 2010. In Person.

Washington State Department of Social and Health Services. *Family Caregiver Handbook*. Aging and Disability Services Administration, 2010. PDF. 2012. <<http://www.dshs.wa.gov/pdf/Publications/22-277.pdf>>.

Permissions for Pictures

Chapter 2:

Womenshealth. *How to read a prescription drug label*. Washington, Dc, USA. August 2010. January 10 2012. <<http://www.womenshealth.gov/minority-health/images/perscriptionLabel.jpg>>.

Womenshealth. *How to read an over-the-counter drug label*. Washington, Dc, USA. August 2010. January 10 2012. <<http://www.womenshealth.gov/minority-health/images/otcLabel.jpg>>.

Chapter 4:

Project Reform. *Anti-HIV Drug Interactions*. New York, NY. 2004. March 3 2012.

<<http://img.thebody.com/legacyAssets/50/11/fsdrugint1.gif>>.

Project Reform. *Anti-HIV Drug Interactions*. New York, NY. 2004. March 3 2012.

<<http://img.thebody.com/legacyAssets/50/11/fsdrugint2.gif>>.