



Helping Hands

Self-Management Guide
For Patients with JIA
and Their Families



Table of Contents

<u>Section</u>	<u>Page</u>
Acknowledgements, Contributions, and Thank You's	3
Introduction to PR-COIN	6
Chapter 1 Your Health Care Team and Expectations	8
Chapter 2 Basic Questions about JIA	25
Chapter 3 Treatment for JIA	48
Chapter 4 Focus on the Family	61
Chapter 5 School Information	73
Chapter 6 Financial Resources	83
Chapter 7 Managing Your Arthritis at Home	87
Chapter 8 Tools and Record Keeping	101
Chapter 9 Website Resources	112
Chapter 10 Word List	115



Acknowledgments

Editors

Janalee Taylor, MSN, ARRN, CPNP

Division of Pediatric Rheumatology
Co-Director Quality Improvement
Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio

Daniel J. Lovell, MD, MPH

Joseph E. Levinson Endowed Chair of Pediatric Rheumatology
Professor of Pediatrics, University of Cincinnati Medical Center
Clinical Co-Director, Division of Rheumatology
Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio

Murray H. Passo, MD, MEd

Professor Emeritus of Pediatrics
Medical University of South Carolina
Division of Pediatric Rheumatology
MUSC Children's Hospital
Charleston, South Carolina

Ronald M. Laxer, MDCM, FRCPC

Professor Department of Paediatrics and Medicine
Division of Pediatric Rheumatology
The Hospital for Sick Children
Toronto, Ontario

Anjie Vago, BA

Education Specialist
Parent Advocate / PR-COIN
Penn State Hershey Children's Hospital
Hershey, Pennsylvania

Esi Morgan, MD, MSCE

Associate Professor, University of Cincinnati College of Medicine
Division of Pediatric Rheumatology
Co-Director Quality Improvement
James M. Anderson Center for Health Systems Excellence
Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio



Contributors

Janalee Taylor, MSN, APRN, CNP
Pediatric Nurse Practitioner
Division of Pediatric Rheumatology
Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio

Murray Passo, MD, MEd
Professor Emeritus of Pediatrics
Medical University of South Carolina
Division of Pediatric Rheumatology
MUSC Children's Hospital
Charleston, South Carolina

Sheetal Vora, MD, MS
Clinical Assistant Adjunct Professor
University of North Carolina
Department of Pediatrics, Rheumatology
Levine Children's Hospital, Carolinas Health System
Charlotte, North Carolina

Nancy Griffin, BSN, MPA, CPHQ
Senior Quality Improvement Consultant
James M. Anderson Center for Health Systems
Excellence
Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio

James Bouslaugh, MS
Special Education
Parent / Coordinator Special Education
Children's Mercy Hospital
Kansas City, Kansas

MaryBeth Burns, BSN, CPN
Care Coordinator
Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio

Laura Bouslaugh, BS
Parent / Human Services Officer
Children's Mercy Hospital
Kansas City, Kansas

Laura Curtis, BBA
Parent / VP Executive Recruitment
Hackensack University Medical Center
Hackensack, New Jersey

Kerry Ferraro, MISM
Parent / Manager, Information Services
Children's Hospital of Philadelphia
Philadelphia, Pennsylvania

Jennifer Gill, BSSW, LSW
Parent / Patient Engagement Specialist
C.S. Mott Children's Hospital
Ann Arbor, Michigan

Melanie Kohlheim
Parent / Patient Engagement Specialist
Nationwide Children's Hospital
Columbus, Ohio

Angela Young
Parent / Patient Engagement Specialist
Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio

The PR-COIN Handbook Workgroup wishes acknowledge and thank the entire Rheumatology Team at Cincinnati Children's Hospital Medical Center for sharing and providing the foundation for this Handbook. An enormous amount of time and effort was spent and we are grateful for their selfless sharing and contributions.

Copyright 2016, Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN). This work was supported in part by grant funding from the Center for Education and Research on Therapeutics (CERTs), AHRQ, Grant #419HS021114.

While the contents of this document including text, graphics and other materials ("Content") may be consulted for guidance, it is not intended for use as a substitute for independent professional medical judgment, advice, diagnosis, or treatment. The Content is not intended to establish a standard of care to be followed in every patient's case. Each patient's case is different; physicians may review the Content for guidance but must use their judgment in determining what is in the best interest of each patient based on the circumstances then existing. PR-COIN endorses no commercial products cited within this document.



Thank You!

Creating a handbook like this one requires the help of many people. Special thanks to the children with JIA and their parents who inspired us in developing the Handbook. We thank the parents involved in working on this Handbook. All of them have children with arthritis. They were essential team members.

A very special thanks to all of the **young artists who were patients** and contributed all of the drawings for the introduction to each chapter of the Handbook!

We would like to thank **Empowered by Kids** (empoweredbykids.com) for sharing stories written by parents and patients who are battling JIA. We are especially grateful to them for having the courage and honesty to share their thoughts, feelings, and experiences with others.

Also, we would like to acknowledge the ImproveCareNow Network for sharing concepts and information from the IBD Self-Management Handbook.

Doctors, nurses, social workers, physical and occupational therapists, psychologists, and customer representatives also helped in developing this handbook. We would like to thank everyone who worked hard to make a handbook that would be helpful to you. This handbook is a result of great teamwork!



PR-COIN

PR-COIN stands for **P**ediatric **R**heumatology **C**are and **O**utcomes **I**mprovement **N**etwork (<https://pr-coin.org/>). PR-COIN is a network of parents, patients, rheumatologists, nurses, therapists, social workers, support, and many others at rheumatology centers. Many of the rheumatologists and health care team members at your hospital are part of PR-COIN.

PR-COIN is a research and quality improvement network. We take the results of research and help to implement them quickly and efficiently through quality improvement practices. We are all working together to improve how care is delivered to children with JIA. Drugs and treatments for JIA have gotten better over the years, but we still need to know more about how to deliver care in the best way. PR-COIN shares information and best practices. This way PR-COIN clinics can find better ways to reduce pain, improve how well joints work, increase children's ability to play, get better treatment results, and so much more.

PR-COIN uses a registry database to measure our performance and goals. All teams learn about the health status of JIA patients in our care and inform future improvement projects. Together we are working to change the way kids with arthritis live their lives and imagine a new world.

While PR-COIN teams are the medical experts, you are the ones living the reality of JIA. PR-COIN joined with parents and formed a Parent Working Group. Parents of patients treated at PR-COIN member hospitals help PR-COIN teams understand what is important to them at home and during their check-ups. You have walked the path of managing JIA seeing its impact first-hand. PR-COIN is also joining with kids, teens and young adults to develop a work group. You have a lot of knowledge, and PR-COIN wants to learn from you. Contact [PR-COIN Parent Workgroup](mailto:Prcoinparents@gmail.com) (Prcoinparents@gmail.com) to learn how you, too, can make a difference!





Chapter 1

You, Your Health Care Team, and Expectations



Let's Get Started

You have been diagnosed with Juvenile Idiopathic Arthritis (JIA). The word idiopathic (id-e-o-path-ik) means “unknown cause.” You may wonder why you have arthritis. You may even feel afraid, mad, or worried. Those feelings are normal. It is important to know it is NOT your or your parents’ fault that you have arthritis. You will have many questions about the arthritis and treatment. You will most likely have questions about day-to-day activities, school or how to help you adjust to all of the changes. Over time, we will talk about all of those things. Our goal is to help you manage your arthritis so you can do all the things you want to do!

We have a team of JIA experts to help take care of you. The team includes doctors, nurses, advanced practice therapists (ACPAC), social workers, physical and occupational therapists, dietitians, schedulers, and many others. But the most important person on the team is YOU! We will work together to come up with the best plan for you. We will need to learn about you and your family. You will need to learn about JIA. The team will help you do that.

This handbook was written to help you learn more about your JIA. **It is very important for you to know as much as possible about your care.**

We hope you will use this handbook and information as a personal book for you to take notes and keep important information. You may feel a little overwhelmed from all of the information given to you here. We will lead you through most of the material. We do not expect you to read this book all at once.

We hope this handbook will be a guide for you and help to ease the road ahead.

We hope you will bring this Handbook with you to your visits. This way you can talk with the team about what you have read or done and help address any concerns or answer any questions.



Let's Talk about Your Health Care Team

Our Rheumatology division believes strongly in the team approach to patient care. This means that there will probably be several different specialists involved in your care. Some of the specialists that *might* be involved in your care are:

Your local doctor (family physician or doctor, pediatrician) – will continue to take care of general medical issues, such as routine childhood illnesses like ear infections, colds, immunizations, etc. This doctor can also work with you pediatric rheumatology team to help you. They will always be updated by letter when you have seen the rheumatologist.

Pediatric rheumatologist – is a doctor with many years of training in taking care of children with different types of rheumatic conditions like JIA or Lupus.

OT/PT Advanced Practice Therapy Practitioner – is specially trained in taking care of children with JIA. They have a Master's degree and work with doctors and families in developing care plans and providing education and counseling about the disease, treatment and resources.

Clinic nurse – will see your child when you come to clinic. They are an excellent resource for helping manage such things as getting your child to take medications, do exercises, use comfort measures and manage pain. Many times the nurse is the link between the family, the doctor, the school, and other members of the health care team and helps to coordinate your child's care.

Physical therapist (PT) – helps with exercises and mobility problems. The PT works mostly with problems in the lower extremities like hips, knees, feet and spine. They also work on overall physical activity. The physical therapist will check your child's joint range of motion, strength, and posture. They will teach you and your child special exercises that you can do at home.

Occupational therapist (OT) – helps with exercises and fine motor skills. The OT works with problems that are in the upper extremities like hands, wrists, shoulders and arms. The occupational therapist will measure upper body motion and strength and may give you special exercises, splints, or other assistive devices to help with activities of daily living (like writing, bathing, or dressing).

Social worker – helps with the personal, emotional, family, or financial concerns which may occur with life challenges. The social worker is also an excellent person to help identify resources within the hospital and local community.



Schedulers – help to schedule your child's appointments and coordinate other appointments or tests that your child may need. They also help with phone calls, making sure you are connected with the right person to answer your questions.

Ophthalmologist – is a doctor specially trained to check for eye disease and take care of any eye problems. The pediatric rheumatologist will help you decide how often your child needs to see the eye doctor.



Important Contacts/Numbers

Local Doctor (Pediatrician):	_____	_____
		Phone number
Doctor(s) (Rheumatologist):	_____	_____
		Phone number
OT/PT Practitioner:	_____	_____
		Phone number
Clinic Nurse:	_____	_____
		Phone number
Social Worker:	_____	_____
		Phone number
Occupational Therapist (OT):	_____	_____
		Phone number
Physical Therapist (PT):	_____	_____
		Phone number
Ophthalmologist/ Optometrist (eye doctor)	_____	_____
		Phone number
Others:	_____	_____
		Phone number

Expectations

What You Should Expect From Your Health Care Team

- Assessment and evaluation at your clinic visits
- Explanation of your test results
- Discussion of treatment options, including which options you prefer
- Monitoring of your response or any side effects to treatment
- To answer your questions
- To talk to you and listen to your opinions and concerns
- To help you learn the skills you need to take care of your daily activities
- Information about available resources
- To check in with you about stress, feelings/emotions, school issues, social concerns, and difficulties with any aspect of your care (like taking your medicines)
- To provide access to a social worker and/or a psychologist who can talk to you in clinic or get a referral to a therapist if needed to help you overcome any difficulties for your family
- Tips to help you remember to take your medications
- To provide clear and simple instructions on how to take care of yourself including taking medications
- To have a non-judgmental discussion about sticking with your treatment plan at clinic visits
- Interest and participation in quality improvement efforts and the opportunity to be aware of or participate in current research if you so choose



Let's Talk about You

The most important member of your health care team is you! You are the expert on you! Your parents, doctors, and nurses will have an idea how you are doing, but you are the only one who can tell us how you are feeling and how your arthritis is doing. You will need to do everything you can to stay healthy.

Having a chronic illness means you must learn new skills. You may need to learn things like how to take medicines, how to do exercises, how to do different treatments, or how to give shots. It can sometimes feel hard to learn all of these things. **There is a great deal you can do at home to help manage your arthritis. This is called self-management.** Past surveys from families have said that self-management or at home management is the #1 priority for them.

There is a great deal You can do at home to help manage your arthritis! This is call self-management.

Your health care team with help you with all of this. Your parents, other family members and health care team will all work with you to come up with the best plan for you. They are there to help you. The main thing is to speak up and don't be afraid to ask questions.

Just because you have a chronic illness doesn't mean that your life does not go on. There are things to do and juggle, school to attend, homework, jobs or work to go to, household chores to do, appointments to go to, medicines to take, treatments to use, insurance concerns, and many other tasks. We want your life to be as normal as possible.

Since this Handbook is all about self-management and learning all you can, we started with that information. We have started with information about what you should expect from your health care team and what the team will expect from you. We have also included lists, based on your age, of what you should know about your arthritis.

Expectations

What We Expect From You

- Take responsibility for your treatment plan
- Keep appointments with your provider and team
- To have a basic understanding of your disease
- Know what medications you are taking and the doses
- Take your medications consistently and as prescribed by your provider
- Let us know if you have any concerns or problems taking your medications or with any of your treatments
- Tell us if you are taking medicines other than those prescribed by your doctor (herbal or alternative medicines/supplements)
- Follow the plan that your doctor, nurse practitioner, dietitian, OT, PT and nurses have developed with you for managing your condition
- Let us know when you have difficulties following the plan outlined by your healthcare team so that we can help
- Communicate openly and honestly about how you are feeling--Tell us when there is stress or other difficulties in your life (e.g. family, school, transportation, or financial concerns)
- Use the skills that we teach you
- Ask questions – **there are no wrong questions, and it's good to have lots of questions**



LEARNING AS YOU GROW



2-4 year old Learning Tasks

Treatment and medical decisions and management are addressed by parents.



- ☐ Child knows name, age, and gender
- ☐ Child has self-care skills (e.g., feeding, dressing)
- ☐ Child follows simple directions
- ☐ Parents support learning body awareness and parts as well as verbal labels for symptoms
- ☐ Parents support daily activities and knowing routines (e.g., play time, bedtime, meals, naps, medications) and what is expected
- ☐ Parents allow some choices (i.e.; order of exercises, or choice between *specified* treats or rewards)

5-7 year old Learning Tasks

Self-management continues to be mainly addressed by parents.



- ☐ You know your address and phone number
- ☐ You help around the house and do “chores” around house
- ☐ You take your medicine that an adult gives you
- ☐ You brush your teeth
- ☐ You eat food that is good for you
- ☐ You do things to keep you safe (like wear your seat belt or wear a bike helmet)
- ☐ You go to school and do your homework

Note to Parents:

☐ *Reward systems such as star charts may be useful for healthy behaviors*

8-11 year old Learning Tasks

☐ You know and can tell some of the signs of your arthritis

☐ You can show how to do your exercises or wear things like shoe inserts

☐ You can take your medicine when reminded; eventually you will be able to take your medicine without reminders



☐ You know and can tell others about your care plan

☐ You take good care of yourself and work to stay clean and healthy

☐ You help to make decisions that are right for you

Note to Parents:

☐ *Encourage your medical team to address your child more directly in care plan discussions*

☐ *May use reward system such as star charts for activities self-management tasks*

☐ *Can use stories to stimulate problem-solving*

☐ *Can role play to rehearse new skills in life-like situation*

12-14 year old Learning Tasks

Self-management is focused on beginning to develop new knowledge and responsibilities.

- ☐ You can explain about your arthritis
- ☐ You can name your medicines and the times you take them
- ☐ You can describe the common side effects of your medicine
- ☐ You know your doctors' and nurses' names
- ☐ You can use a thermometer
- ☐ You can answer at least 1 question during your visit to the doctor
- ☐ You can manage your arthritis needs at school
- ☐ You are learning how to call your doctor's office
- ☐ You are getting ready to be able to take your medicine on your own



Note to Parents: taking away parent support and direction is a ***slow and personal process***. Parent support in chronic care is linked to improved outcomes.

15-17 year old Learning Tasks

- ☐ You know your medical history
- ☐ You can answer many questions during your office visit
- ☐ You spend part of the time during a visit alone with your provider
- ☐ You know how to get more information about your arthritis
- ☐ You know the names and purposes of the tests that are done
- ☐ You know what can trigger a flare of your arthritis
- ☐ You know what might happen if you don't follow your treatment and plan
- ☐ You know how to re-order your meds and call your provider for refills
- ☐ You can call your provider's office to make or change an appointment
- ☐ You have talked with your provider about how your arthritis and treatment may be affected by drugs, alcohol, or cigarettes
- ☐ You have talked with your provider about the impact of your arthritis or treatment on your sexual activity



Note to Parents: taking away parent support and direction is a ***slow and personal process***. Parent support in chronic care is linked to improved outcomes.

18+ year old Learning Tasks

Self-management is focused on the young adult taking charge.

- ☐ You can describe what medicines you should not take because they may have an effect on the medicines you take for your arthritis
- ☐ You can manage all of your medical tasks outside the home (school, work, etc.)
- ☐ You have a private visit with your provider or choose who is with you during a check-up
- ☐ You call to report flares, other changes in symptoms or questions / concerns
- ☐ You have talked with your provider about the impact of your arthritis or treatment on your sexual activity
- ☐ You have booked your own appointments, re-filled prescriptions, and contacted your medical team
- ☐ You can tell someone your legal rights and responsibilities when you turn 18
- ☐ You carry your insurance card with you
- ☐ You know how long you can be covered under your parents' health insurance plan
- ☐ You know when to expect to change or transition to an adult arthritis provider
- ☐ You have discussed your transition needs and plans with your provider
- ☐ You have made plans to find an adult primary care provider
- ☐ You have talked with a member of your health care team about vocational rehab, driving, college office for students with disabilities, financial aid, etc



Responsibility Worksheet

	Specific Goals and Activities
Basic Knowledge About Arthritis	<i>Example: Know about JIA and symptoms</i>
	Specific Goals and Activities
Office or Provider Visits	<i>Example: Asking questions on my own</i>
	Specific Goals and Activities
Medicines	<i>Example: Filling my prescriptions, bill box, knowing the dose of medicine</i>
	Specific Goals and Activities
Other treatments or information	<i>Example: exercises, insurance, college information</i>



Notes

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Chapter 2

Basic Questions



Juvenile Idiopathic Arthritis (JIA)

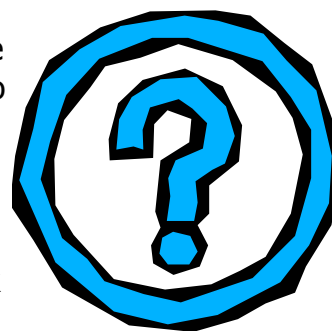
WHAT YOU SHOULD EXPECT FROM US

- To provide you information about JIA
- To explain details of your arthritis
- To answer your questions

WHAT WE EXPECT FROM YOU

- To have a basic understanding of JIA
- To have a basic understanding of your arthritis
- To ask questions

You have been diagnosed with juvenile idiopathic arthritis (JIA). We have found there are common questions that are asked. We tried to list and answer some of the most common questions in this chapter. This will be your introduction to JIA. Some of the questions may sound familiar or you may have already discussed them with your provider. You may also have questions about some of the medical words you find in the Handbook. We have a “Word List” in the back of the book which explains these.



1. WHAT DO WE CALL IT?

There are several types of JIA. This chapter will discuss the different types of JIA. Some children have arthritis that is very mild and limited to one or just a few joints. Other children may have severe arthritis and total body symptoms. Some of the symptoms can be high fever, rash, and swollen glands. This is called systemic (sis-tem-ik) disease. Some examples of different types of arthritis are systemic (multiple body symptoms), polyarticular (pol-e-r-tic-u-lar) which is 5 or more joints, or psoriatic (sore-e-at-ik) arthritis. The different types of JIA are reviewed later in this Chapter.

2. HOW COMMON IS THE DIAGNOSIS OF JIA?

JIA is the most common type of arthritis in children. It is a long term disease. About 1 in 1,000 children have JIA. The number of new cases per year is about 9 per 100,000 people.

3. HOW DO WE MAKE THE DIAGNOSIS?

We have to make sure you do **not** have any other conditions or types of arthritis that could look like JIA. The healthcare team will ask you questions and review your symptoms and do a careful head-to-toe physical exam. It is also important to review your past medical history and your family's past medical history.

Arthritis is defined as an inflammation in a joint that can cause swelling or painful loss of motion in one or more joints. In order to diagnose JIA, arthritis must be present for at least 6 weeks in a row in the same joint. The arthritis may be in one or more joints. Children with systemic JIA often have high fever, rash, and enlarged glands. The systemic features (meaning those outside the joints) usually come before or at the same time the arthritis is present.

There are several blood tests that help to find out if you have JIA or something else. The tests by themselves do **not** prove you have JIA. The tests look for markers inside the body or signs of arthritis. The physical exam and the history are just as important as the blood tests.



X-rays of the joints with arthritis are often done. They can be helpful to exclude other diseases or to help follow the effects of the arthritis on the cartilage and bone. Specific lab tests and x-rays are discussed later in this chapter.

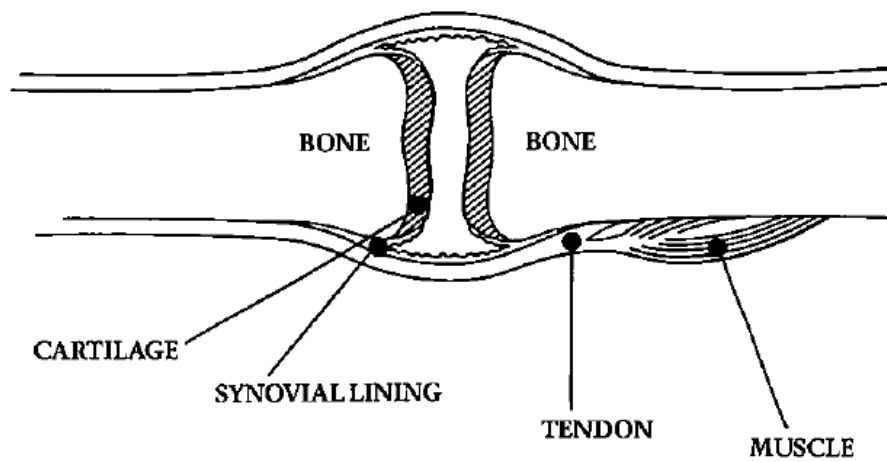
4. WHAT IS GOING ON INSIDE THE JOINTS?

The word “arthritis” means inflamed or swollen joint. The arthritis can affect the lining of the joint. This lining is called synovial lining, or synovium (si-nō-vē-um). (See picture on the following page.) The synovium makes fluid that provides nutrition to the cartilage. The cartilage is a cushion for the joint. When the lining gets inflamed, it makes more fluid. The synovium becomes swollen. This causes swelling that you can feel and see on the outside of the joint. The swelling can be painful and cause stiffness. It can make the joint hard to move.

There is a complex process going on in the synovium with different kinds of white blood cells and chemicals which cause the swelling. This process could eventually damage the cartilage and bone. Research is going on to find out more about these types of white blood cells and the chemicals that are being released into tissues and fluid.

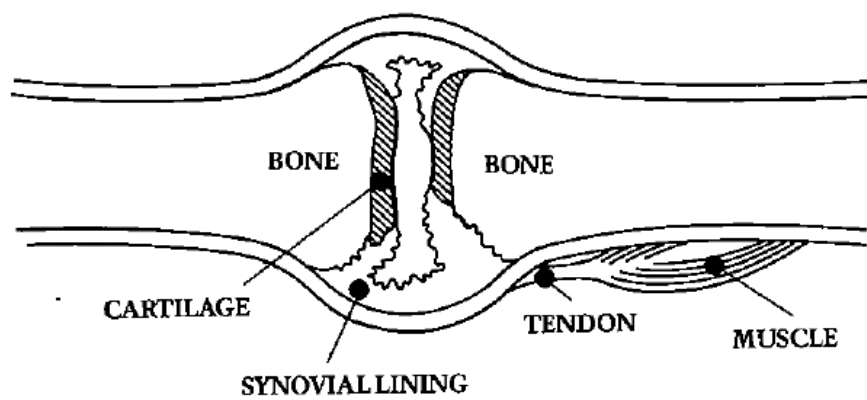
Illustration of the Joints

NORMAL JOINT



ABNORMAL JOINT

JOINT WITH ARTHRITIS



5. WHAT CAUSED THE ARTHRITIS?

The exact cause of JIA is not known. JIA is thought to be caused by a mix of genetics and the environment. Some kids may be more likely to get arthritis because of their family genes. Different genes are involved in the types of JIA. Researchers think that something in the environment 'triggers' the body's defense system called the immune system. The environment seems to be more important in systemic JIA. Things in the environment that could affect getting arthritis may be bacteria or virus infections.

Even though we do not know the exact cause of JIA, researchers have learned a lot. We know there are several natural chemicals or proteins in the body that increase swelling in the joint. Learning about these chemicals has led researchers to develop new and very effective medicines. We expect that more medicines will be developed in the future. These medicines are discussed in more detail in Chapter 3, "Treatment".

6. IS THERE A CHANCE OTHER FAMILY MEMBERS, PARTICULARLY OTHER CHILDREN IN THE FAMILY, WILL ALSO GET THE ARTHRITIS?

JIA is not contagious. Even though we have mentioned infection and genetic factors, it is **not** common for other people in the family to develop this arthritis. There are some cases of JIA happening in families, but this is very rare. As a matter of fact, one part of ongoing research is to keep a National Registry of all the brothers and sisters with JIA so that we study why their families were affected in that way.

You may ask how this relates to other family members who already have some type of arthritis. Arthritis is one of the most common chronic conditions. The most common form of arthritis is **osteoarthritis**. Many people have older family members who have osteoarthritis. Osteoarthritis is not the same as JIA that you have developed. There may be a connection if there is **rheumatoid** arthritis in other family members, but it is still unclear how this links to your JIA. There are certain genes that are more common in different types of arthritis. However, the genetic component of arthritis is not yet fully understood.

7. WILL IT SPREAD, GET WORSE, OR CAUSE DISABILITY?

This is probably one of the most common questions that is asked. Unfortunately, we cannot say exactly what will happen to you and if the arthritis will eventually go away or stay for a long time, or spread to other joints. Some children will have only one joint affected during the entire course of their JIA; other children will start with one joint and it will spread to affect several joints, both large and small. In some kids, the disease remains mild and easy to control. In other patients, it is more severe and difficult to control. Some of the blood tests help us to understand that a child may have more serious arthritis. However, these tests are not exact. Most children do **not** become "crippled" from this disease. This,



however, is based on starting medicines early as well as a physical therapy program for the joints (usually done at home each day). We will discuss more on the management and treatment of this disease in additional questions.

Most kids with JIA grow and do what they want to do as they get older. However, some kids may have trouble with pain in their joints and even ongoing swelling. Research shows that the children finish high school, get college educations, have great successful jobs, get married, and have kids if they want to as well as or better than the general healthy population.

8. WILL THE DISEASE PERSIST OR RECUR IN ADULTHOOD?

There is some information available about having ongoing arthritis in adulthood. About half of the kids with arthritis will still have arthritis after 10 years. We also know that the disease might come back when you are an adult, even if it went away for a while. This can especially happen in those kids and teens who got JIA during late school age or as a teen. The exact numbers are not known on how many kids will have JIA as an adult. We should remain optimistic as treatment options are constantly improving.

We are hopeful that as new medicines and other treatments come along that kids with JIA will be able to function and do all the activities they want to as they become adults.

9. WHAT CAN BE DONE TO TREAT THE ARTHRITIS?

The treatment for JIA has many parts. Information is shared back and forth with each member of the team. Every team member, you, your parents, doctors, nurses, physical or occupational therapists, eye doctor, or psychologist, has a special part in the treatment. Not all kids will need to see every team member; however, children with multiple affected joints often see these health care providers off and on through the course of their disease.

Specific medicines for the arthritis are reviewed in detail in Chapter 3, "*Treatment*". Briefly, we often use steroid joint injections to decrease the joint pain and swelling. Other medicines that are often started are NSAID's or **Non-Steroidal Anti-Inflammatory Drugs**. Examples of NSAID's are: Ibuprofen, Naproxen, Meloxicam, or Celecoxib. Many kids often need to add other medicines or treatment for the arthritis. Other treatments include DMARD's or **Disease Modifying Anti Rheumatic Drugs**, or Biologics. All of these medicines work against pain and swelling. These other meds are also discussed in Chapter 3.

The question asked often is about how the foods you eat can affect your arthritis. You may wonder if adding or avoiding foods can be helpful in treating the arthritis. Some research has been done regarding the effect of food on arthritis. There are some foods that have anti-inflammatory effects. However, there is no definite diet for arthritis. We always support a well-balanced, nutritious diet with plenty of vegetables and fruits. If you have questions about different types of foods please discuss these with the doctor, nurse, or ask to see a



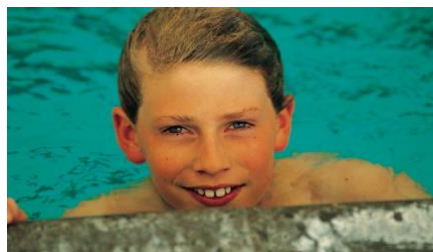
nutritionist. Some medicines may need you make some changes in the foods you eat. These would be talked about separately if you need one of those medicines. Sometimes there are special concerns about the growth of children with different types of JIA. Your height and weight will be checked at your visits. Your team will let you know if you need any special treatment.

10. WHAT ABOUT SCHOOL, SPORTS, OR OTHER ACTIVITIES?

School is very important, both for learning and being with your peers. The majority of kids attend school regularly. However, special plans or changes may need to be made to make the most of your school experience. We will work closely to help you work with the school to make sure you are successful. There is additional information in Chapter 5, *'School Issues'* regarding school activities and working with the school.



School concerns are important to discuss with your health care team. Sometimes certain changes are needed when your arthritis is very active or causing problems. We want you to attend school every day and take part in physical activities when possible. Impact-loading or contact sports, such as basketball or football, may be too hard on your joints and possibly harmful for your joints. Your age and the demands of the sports program are also important factors. Swimming, bicycling, walking, and other strengthening exercises are all low impact activities and are strongly encouraged. PE class is also important and can be changed if necessary so that you can participate. These options should be discussed in more detail with your team.



11. WHAT ARE THE LABORATORY TESTS THAT ARE ORDERED TO HELP MAKE THE DIAGNOSIS?

There are several important points about laboratory tests. The first is that **none** of the tests tells us for sure that you have arthritis. That means that the diagnosis cannot be made by lab tests alone. The diagnosis is made by history and physical examination. The lab tests help to find out the type of arthritis, identify markers to help predict how the arthritis will do over time, and exclude other illnesses or conditions. In addition, lab tests can help us to monitor your arthritis and detect any side effects from medicines.

The first test that is often discussed is the sedimentation rate, **ESR**, or "sed rate." Sometimes we also check the C-Reactive Protein, **CRP**. Both of these tests show how much inflammation is in your system. The sed rate or CRP will vary from patient to patient. Some patients have normal values but still have arthritis. Other patients may have very high values, but do not appear to be seriously ill. Common infections cause inflammation in the body and can also elevate the sed rate or CRP.



Another common test is the antinuclear antibody test or **ANA**. The ANA is a screening test. It is a protein which is made by the white blood cells. The ANA test is the most common test to be positive in children with JIA. It is often called the "lupus" test. However, in kids it is more common for patients with a positive ANA to have JIA. The ANA test is positive in about 2/3 of children with oligoarticular JIA and about 1/3 (or more) of children with polyarticular JIA. Also, the ANA is a marker for patients at higher risk for getting the eye inflammation that is associated with JIA. Information about eye problems in JIA is discussed in more detail at the end of this chapter. Remember, the ANA does not diagnose arthritis or eye problems. It has to be used along with the history and physical exam to help determine if you may have eye involvement with the arthritis.



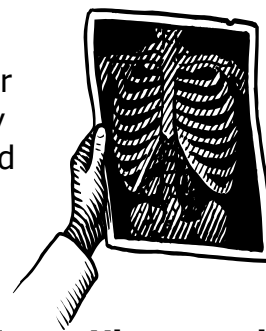
The **rheumatoid** (rū-mă-toyd) **factor** and **anti-CCP** are tests that can be positive in rheumatoid arthritis. When the rheumatoid factor or anti-CCP test is positive, it often means you may develop polyarticular JIA. These tests can be very useful in the early diagnosis of arthritis and to say you may need certain medicines sooner or quicker. Again, the rheumatoid factor and CCP must be used along with the history and physical exam. Rheumatoid factor is commonly positive in adults with Rheumatoid Arthritis but uncommon in JIA.

Other common tests include the **complete blood count, liver function, kidney function, and muscle enzymes**. These are ordered based on your signs, symptoms, or which medicines you may be taking. The complete blood count (CBC) helps to look for anemia (low red blood cell count). Patients with JIA can sometimes have anemia. These tests are a way to watch for any problems that cannot be detected by physical exam or by history.

Another test that may be done is **HLA-B27**. This is a gene that is present in about 70-90% of patients with arthritis that affects the spine and in enthesitis related arthritis (ERA), which we will discuss later in the chapter. It is also positive in about 4% of healthy people so it needs to be assessed along with other aspects of the patient.

12. WHAT OTHER TESTS MIGHT BE DONE TO HELP MAKE THE DIAGNOSIS?

X-rays are often ordered to evaluate the bones and joints. Early in arthritis, the bones are often x-rayed to check for fracture, infection, or tumors. Later, x-rays can help as a way to follow whether there is any damage to the bone or loss of cartilage due to the arthritis. This could take a long time to show up. When x-rays are ordered for you, the doctor will explain why the x-rays are being done. Remember that the synovium (lining of the joint) and fluid cannot be evaluated on x-rays.



There are also other ways to evaluate the joints and swelling in arthritis. **Ultrasound** and **MRI (Magnetic Resonance Imaging)** are often helpful to see if you have arthritis and look at the joint and surrounding tissues.



Ultrasound uses sound waves to image inflamed joints, synovium, and tendons. This can often be done in the clinic or radiology. It is painless and there is no radiation.

MRI scan is a test that produces very clear pictures of the joint and other parts of the body. MRI uses magnetic radio waves and a computer to make pictures of the joint. This does not give you any radiation. MRI is helpful to look at inflamed joints and surrounding tissues. MRI can be used detect arthritis.



There are many questions you may have as you start to learn about JIA. Over time, we hope to be able to answer all of your questions. Remember that it takes time to learn all of these different points. This handbook can be taken home so you can review the information at your own pace. As questions come up, please make a list of items to discuss with your nurse, doctor, social worker, nutritionist, or therapists.

Different Types of Arthritis

Oligoarticular JIA

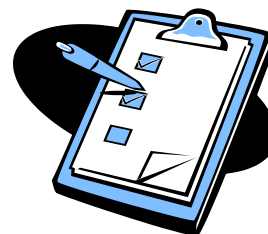
Oligoarticular (ō-li-gō-ă-r-tic-ŭ-lăr) is the most common form of JIA. "Oligo" means few. By definition, this form of JIA **has 4 or less joints** involved during the first 6 months of disease. About 40% of patients with oligoarticular JIA will go on to develop arthritis in more than 4 joints over the course of the next few months to years. This is sometimes called **extended** oligoarticular JIA. This is because the arthritis went on to involve more than the original, four or less, joints to involve many joints, five or more.

Young girls with oligoarticular JIA and positive ANA are at the highest risk to develop inflamed eyes. This is called **iritis** or **iridocyclitis** (ear-ri-dō-sī-clī-tis) (see page 40). For this reason, this group of children is checked by the ophthalmologist (eye doctor who went to medical school) more often for possible inflamed eyes. The highest chance of getting inflamed eyes is in the first 7 years of your arthritis. You will need to visit the eye doctor up to 3 to 4 times per year in the first 7 years. After 7 years, you will need to have your eyes checked once a year for the rest of your life. This is because the iritis may not cause symptoms or hurt and you will not know your eyes are inflamed. The iritis can cause lasting problems and you may not be able to see if it is not treated.



CHECK LIST FOR DISCUSSION WITH YOUR PROVIDER:

- ☐ Discussed how many joints are affected
- ☐ Discussed the significance of the ANA test
- ☐ Discussed iritis
- ☐ Discussed ophthalmologist (eye doctor)
- ☐ Discussed prognosis



JIA, ERA and Psoriatic Types

JIA affecting few joints can also occur during late school age or adolescence, often in boys. It is believed that there is a link between oligoarticular JIA and a type of arthritis called **spondyloarthritis (SpA)**. “Spondylo” means spine; “arthritis” means inflamed or swollen joint. These patients can have arthritis in the hips, knees, ankles, toes, and shoulders. Involvement in the hands, wrists, and elbows is much less common. The heels and tendons can also become inflamed.

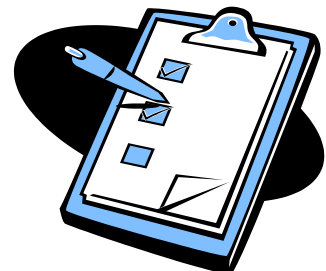
Enthesitis-related arthritis (ERA) is another type of JIA. Enthesitis (en-tha-SI-tis) is swollen or inflamed tendons or ligaments where they attach to bone. Both enthesitis and arthritis can occur in ERA. Between 10% and 15% of all children with JIA have ERA. It is usually seen in late childhood or adolescence (8 to 15 years of age). It affects boys more often than girls. ERA can be mild and last only a short time. For others, it can be more severe and last a long time. The eyes, bowels, and skin can be involved in ERA. Up to 30% of children who have ERA can develop inflamed eyes, which is typically very painful and has a sudden onset. You should see the eye doctor right away if this happens. ERA is sometimes referred to as spondyloarthritis.



Another subtype of JIA is **Psoriatic Arthritis (PsA)**. Patients with PsA develop inflamed skin and arthritis. The inflamed skin is called psoriasis. The psoriasis may occur either before or after the onset of arthritis. Symptoms of psoriasis may include a scaly, pinkish-red, itchy rash on the knees, elbows, scalp, face, and folds of the buttocks. Psoriasis also affects the nails. Joint involvement often starts in fingers and toes but can include larger joints. Lastly, patients can also develop inflamed eyes. This also often has a sudden onset with red and painful eyes. It is common for relatives to have psoriasis even if not with the arthritis.

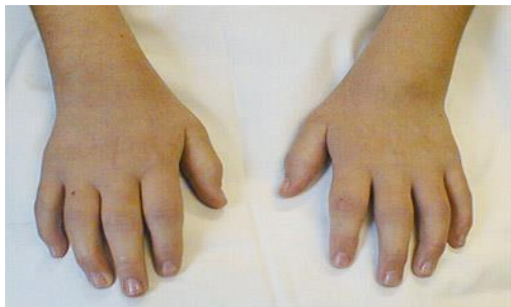
CHECK LIST FOR DISCUSSION WITH YOUR PROVIDER:

- ☐ Discussed how many joints are affected
- ☐ Discussed the overlap of JIA and spondyloarthropathy
- ☐ Discussed eye involvement
- ☐ Discussed possible bowel problems



Polyarticular JIA

Polyarticular JIA involves **5 or more joints** in the first 6 months. "Poly" means many. Patients with polyarticular JIA commonly have arthritis in both large and small joints. The arthritis is often symmetrical (si-met-tree-cal). This means the arthritis is often present in both knees, or both ankles, or both wrists, etc. However, any joints (the neck, jaws, fingers, toes, and all the other large joints) can be involved. The neck (or cervical spine) is often involved in this type of JIA. Arthritis in the low or mid-back is uncommon.



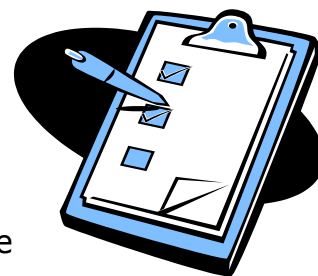
Kids with polyarticular JIA can have some features that affect the entire body, such as low-grade fever, weight loss, reduced appetite, mild lymph node or gland enlargement, and low-grade anemia. Problems of the heart, lung, and kidney are rare; however, we will watch for involvement in other areas of the body in addition to the joints.

Most children who have polyarticular do not have a positive rheumatoid factor blood test like many adults with arthritis. The presence of rheumatoid factor suggests the arthritis may be very similar to adult rheumatoid arthritis. These children (mostly girls with onset of disease during late school age or adolescence) may have the other features of adult rheumatoid arthritis. These would include nodules or bumps under the skin and the potential for inflamed small blood vessels. We will talk with you more about these features **if** they occur.

Polyarticular JIA patients are at less risk for developing inflamed eyes. Inflamed eyes occur in only about 5 of 100 kids with polyarticular JIA. The slit lamp exams need to be done every 3 or 6 months for the first few years of disease depending on ANA test.

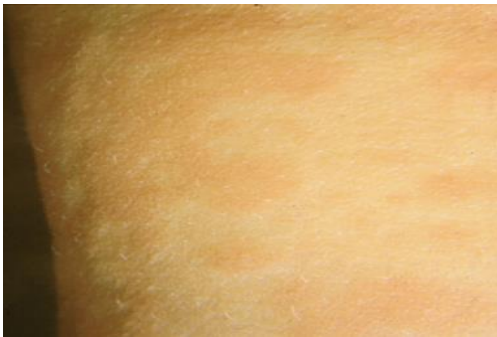
CHECK LIST FOR DISCUSSION WITH YOUR PROVIDER:

- ☐ Discussed how many joints are affected
- ☐ Discussed "symmetrical" involvement and what it means
- ☐ Discussed eye involvement and 6 month checks with the eye doctor
- ☐ Discussed the results of the rheumatic factor test and what it means for you



Systemic JIA

Systemic JIA is the form of arthritis which can affect the entire body or "system," often before it affects the joints. The most common symptom is a fever which usually occurs once or twice a day. The fever is usually quite high, with temperatures 103° or higher. This fever typically occurs in the late afternoon or the evening. During the fever, you can look and feel quite ill. When you do not have a fever, there will be fewer signs or symptoms of the disease.

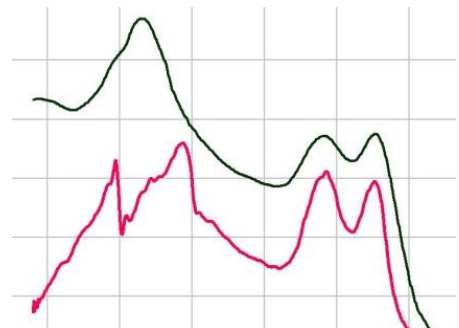


During the times of fever, there is often a rash. This rash comes and goes. Only about 1 in 20 children will complain of any itching with the rash. The rash is **not** contagious. The rash is often present wherever there is pressure on the skin. An example is under the elastic of underwear or where the skin has been scratched. The rash also comes out whenever the skin is hot from exercise or even outside temperature. Even taking a warm bath may bring out the rash.

The lymph nodes or glands, liver, and spleen are organs which react to the inflammation. They can become somewhat enlarged (bigger) in about 6 out of 10 children. The enlargement is not dangerous.

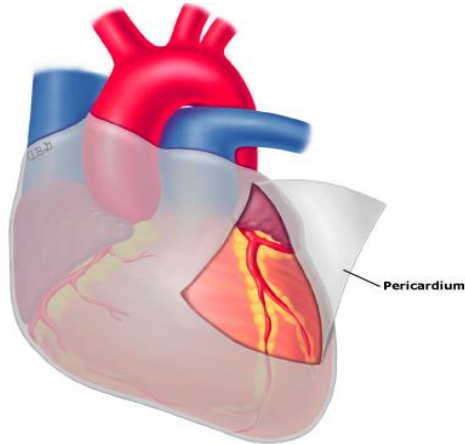
Eventually, most children will develop arthritis in at least a few joints. This can be a very difficult form of arthritis. It can come and go with the systemic features. It is not possible to tell if the arthritis will stay for a long time or go away when the symptoms of fever and rash go away. This will take time to "chart a course" of how your systemic or total body arthritis will come and go.

Many patients with systemic JIA can become quite anemic and have low iron over the course of the first few weeks of their condition. The anemia can be severe in some patients but rarely requires transfusion. Usually, the white blood count and the platelets are very high. We will need to monitor the anemia for any changes over time. Your provider can watch your blood counts like in the graph at the side.



Systemic JIA

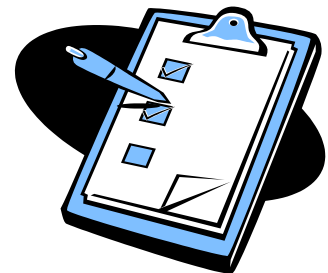
Patients with systemic JIA are often very tired. This is due to effects of inflammation and anemia. The inflammation also causes loss of appetite and can affect growth. Usually the entire body features (fever, rash, enlarged glands) of systemic JIA last for several weeks to several months. It is unusual for the systemic features to last indefinitely; however, this does occur in rare cases.



Sometimes the outer lining of the heart, the pericardium, can become inflamed in some children with systemic JIA. It only becomes serious in a small group of sometimes have symptoms of chest pain, shortness of breath, or pressure in the chest. If this would occurs, it is important to notify the doctor or nurse right away so they can evaluate and treat you if needed.

CHECK LIST FOR DISCUSSION WITH YOUR PROVIDER:

- ☐ Discussed fever pattern
- ☐ Discussed rash
- ☐ Discussed anemia
- ☐ Discussed swollen lymph nodes
- ☐ Discussed pericarditis and symptoms to watch for
- ☐ Discussed growth and appetite issues



Iridocyclitis—Uveitis, Iritis

All children and adolescents with JIA are at risk to develop inflamed eyes as well as arthritis in the joints. This is not a type of arthritis but a complication which can happen.



About 20% of patients with JIA will develop uveitis (u-v-i-tis) or iritis. The risk of developing eye disease is highest in the first 7 years of onset of the arthritis. The most common onset is between 2 to 4 years of age. Girls who are ANA positive with a fewer number of joints involved (oligoarticular) have a higher risk of developing eye disease; however, studies suggest boys with eye disease have higher complication rate.

Eye inflammation can occur in many parts of the eye. The exact term for inflamed eyes depends where in the eye inflammation is located. It often occurs in the middle part of the eye or uveal tract. When it occurs in the uveal tract it is called uveitis. There are 3 parts to the uveal tract:

- The iris –colored part of the eye
- The ciliary body –part of the eye that releases clear liquid
- The choroid –part of the eye filled with blood vessels that bring oxygen and nutrition to the eye

Inflammation that occurs inside the eye is called uveitis if it affects one or more parts of the uveal tract, the middle layer of the eye (see Figure on page 43).

Most of the time, in JIA, the inflammation is in the iris or ciliary body. This rarely causes symptoms of blurry vision, pink or red eyes, squinting or eye pain. Inflamed eyes can happen without having arthritis. Thus you can have eye inflammation while the arthritis is gone. The opposite can also happen. You could have active arthritis and no problem with your eyes.

Since few or no symptoms are often present, we **must** check for inflammation on a regular basis. To detect eye inflammation, an eye doctor does a slit lamp examination. This is a brief, easy and painless test that can be performed even on young children (see page 44). The slit lamp examination needs to be done at regular intervals for several years after the initial diagnosis of JIA. At the initial appointment, you will need to have your eyes dilated so they can check for inflammation in the back of the eye (vitreous and retina, See page 43). How often you need to get a slit lamp exam depends on what type of JIA you have, your age when you were diagnosed, and if your ANA is positive. The arthritis team and eye



doctor will work together to let you know how often you need to have a slit lamp exam. It is important for you to keep track of the eye exams and follow the schedule.

Remember, you can lose your eyesight if the inflamed eyes do not get treated. Treatment requires that you take the prescribed medicine and go to your follow up exams. Untreated or under-treated uveitis can cause eye damage and vision problems.

If the eye doctor finds inflamed eyes, they will initially prescribe eye drops to decrease the inflammation. They may also give you another eye drop that makes the pupil (black middle circle) bigger. (See page 45 on Tips for Inserting Eye Drops)



The eye drops are in addition to the treatment for joints. The medicines prescribed by your provider tend to help both the joints and the eyes.

Additional Resources for Patients and Family:

- 1) American Association for Pediatric Ophthalmology and Strabismus. Juvenile Idiopathic Arthritis.
<http://www.aapos.org/terms/conditions/63>
- 2) American Uveitis Society. Juvenile Idiopathic Arthritis Associated Uveitis
<http://www.uveitisociety.org/pages/diseases/jia.html>
- 3) American Academy of Ophthalmology EyeWiki.
[http://eyewiki.aao.org/Juvenile Idiopathic Arthritis](http://eyewiki.aao.org/Juvenile_Idiopathic_Arthritis)
- 4) Online Pediatric Uveitis Support Groups for Family, Kids and Teachers:
<http://www.uveitis.org/patients/online-support-group>
- 5) Borden, Molly. I have Uveitis? A Book About Uveitis for Children. Available:
<http://www.uveitis.org/store/product/i-have-uveitis-a-book-about-uveitis-for-children>
- 6) Canadian Ophthalmological Society:
<http://www.cos-sco.ca/vision-health-information/conditions-disorders-treatments/retinal-diseases/uveitis/>
- 7) College of Optometrists of Ontario:
<https://www.collegeoptom.on.ca/>

CHECK LIST FOR DISCUSSION:

- ☐ Discussed iritis and reviewed pictures
- ☐ Discussed risk of eye involvement
- ☐ Discussed how often to get slit lamp exam



Illustration of the Eye

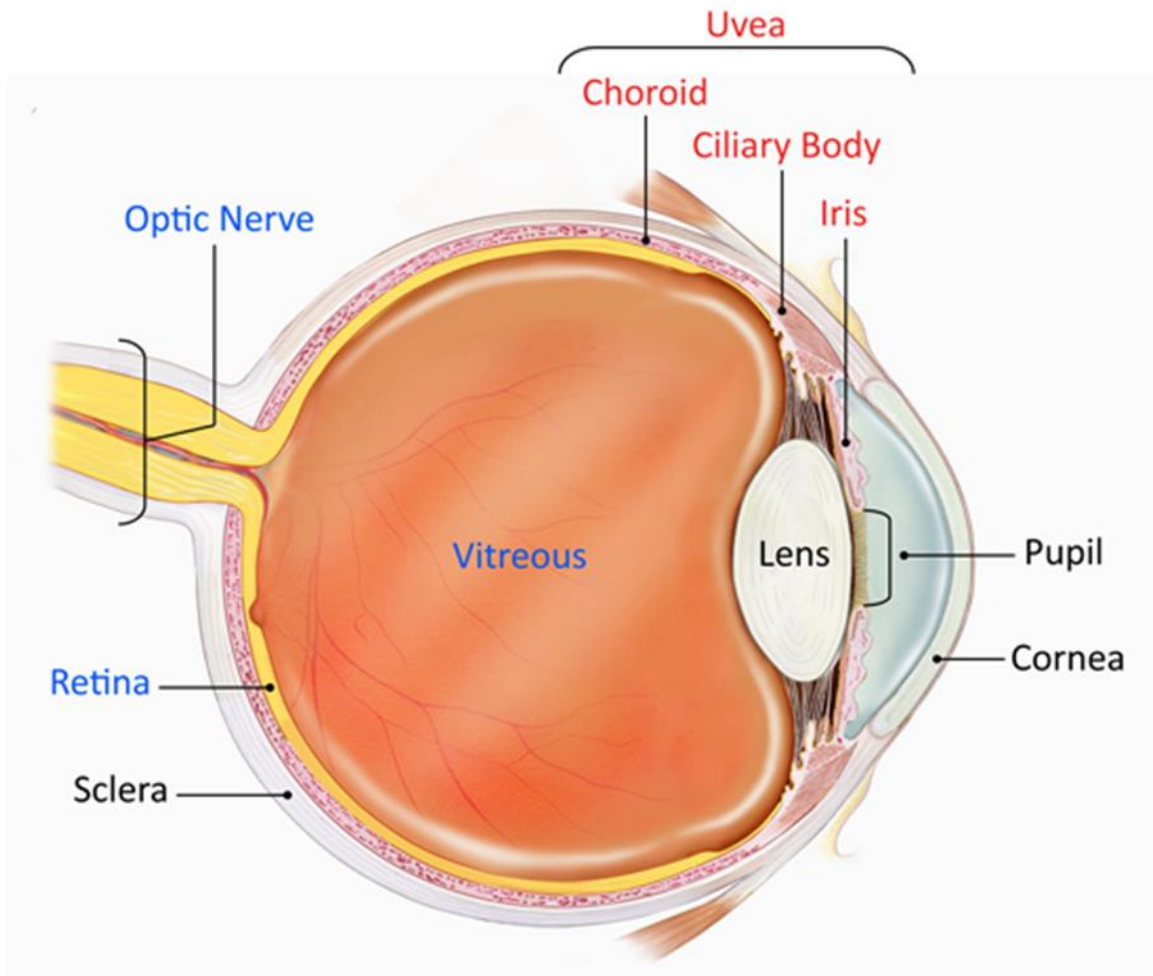


Diagram of the eye: In JIA, inflammation usually occurs in the space between the pupil and the cornea, but in some cases can affect even the vitreous or retina. To detect inflammation, eye specialists do a slit lamp and dilated examination.

“Courtesy: National Eye Institute/National Institute of Health (NEI/NIH)”

Slit-Lamp Exam

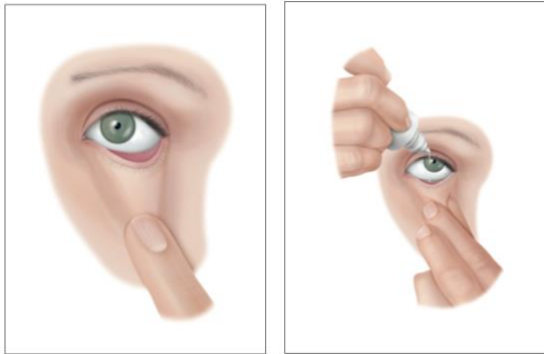


An eye specialist is performing a slit lamp examination on a patient.

"Courtesy: National Eye Institute/National Institute of Health (NEI/NIH)"

Tips for Giving Eye Drops

- 1.) Wash your hands prior to using eye drops.
- 2.) Shake the bottle.
- 3.) Remove the cap and do not touch the dropper tip.
- 4.) Have your child tilt his or her head back slightly (or lie down flat on his or her back).
- 5.) Pull his or her lower eyelid away from the eye to form a pocket.



- 6.) Have your child close his or her eyes and apply pressure to the point where the eyelid meets the nose (this prevents the eye drops from draining into the nose).



- 7.) If your child is prescribed more than one type of eye drop, always wait 10 minutes before using a second drop. Otherwise, the 2nd drop will rinse out the first drop and prevent it from working.

Images courtesy of the American Academy of Ophthalmology.

Let's Review:

1.) What type of arthritis do you have? _____

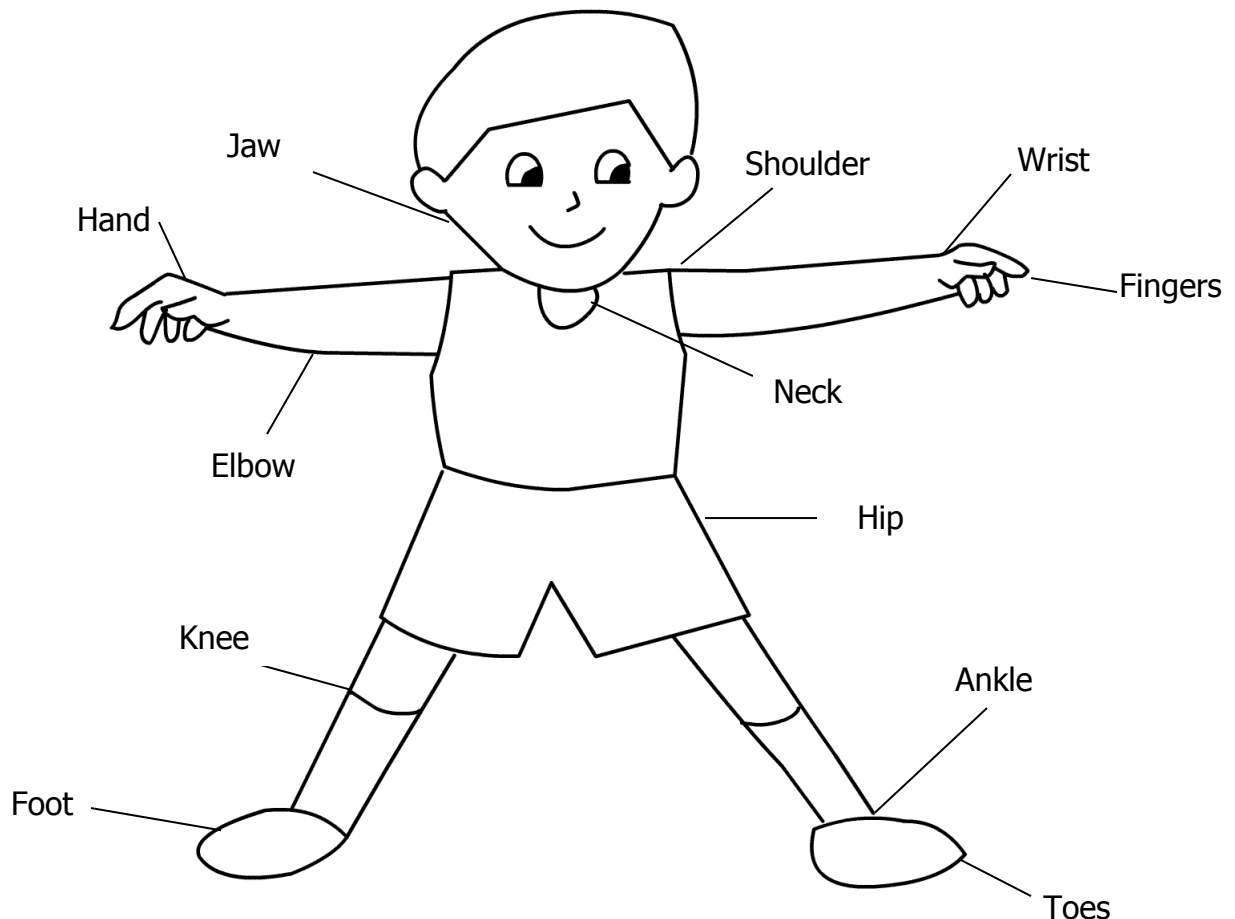
2.) All types of arthritis are the same (circle the right answer).

- ☐ True
- ☐ False

3.) Which of the following are symptoms of JIA? (check the right answer or answers)

- ☐ Joint pain
- ☐ Joint swelling
- ☐ Stiffness
- ☐ All of the above

4.) Circle or mark YOUR joints that have arthritis.



Notes

[illegible]

Chapter 3 Treatment



Treatment Goals for JIA



- Help you learn about your arthritis and how to manage your arthritis at home
- Control swelling, pain and stiffness
- Avoid side effects of medicines
- Keep your joints moving and preserve full range of motion
- Increase muscle and joint strength (children lose strength around their joints if they are swollen for too long)
- Make sure you are growing normally
- Make sure you are happy, able to go to school and do the things you want to do with your family and friends
- Make sure you are able to come to office visits and get the medicines and treatments you need

All of these goals can be reached with you, your family, and your health care team working together.

WHAT YOU SHOULD EXPECT FROM US

- Up to date information about available treatment
- Checking and watching for side effects to medicine
- Talking with you about treatment choices

WHAT WE EXPECT FROM YOU

- Take your medicines exactly as they are prescribed
- Tell us if you have any worries or problems taking your medicines or any of your treatments
- Tell us if you are taking any medicines other than those prescribed (for example vitamins, herbs, or supplements)
- Ask questions

Drug Treatment

There are many types of medicines used to treat arthritis. The medicines work in different ways and have different side effects. Your provider will explain, in detail, the special ways these types of medicines work in your system. The main groups of medicines are listed below:

1. Non-steroidal anti-inflammatory drugs (NSAID's)
2. Disease Modifying Anti-Rheumatic Drugs (DMARD's)
3. Corticosteroids
4. Biologics
5. Experimental or investigational agents

There is a lot of research going on to test new medicines and treatments for JIA. There is always attention paid to safety and how well the medicine works. If there is a new medicine that could possibly help you, then your health care team may talk to you about a research study. All of the details would be explained and consent is always obtained before any study medicine is used.



The decision to choose a medicine for you will include several points:

- your age
- your type of arthritis and joints involved
- how long you have had the arthritis
- severity of disease
- previous medicines that have worked or failed
- possible side effects
- how soon it will work
- how the medicine is given
- allergies to medicines



NonSteroidal Anti-Inflammatory Drugs (NSAIDs)

EXAMPLES

Generic Name:	<u>Celecoxib</u>	<u>Naproxen</u>	<u>Nabumetone</u>	<u>Meloxicam</u>
Brand Name:	CELEBREX®	NAPROSYN®	RELAFEN®	MOBIC®

Non-steroidal anti-inflammatory drugs (NSAID's) help decrease swelling, pain, stiffness, and warmth in the joints. They may also help fever. Improvement can begin within 1-2 weeks, but the full benefit may not be seen for up to 12 weeks.

Possible Side Effects:

- Stomach ache or pain, nausea, loss of appetite, rarely ulcers
- Easy bruising, nosebleeds
- Rash, hives, or itching
- Photosensitive (light sensitive) rash
- Rarely affects the kidneys, liver, blood

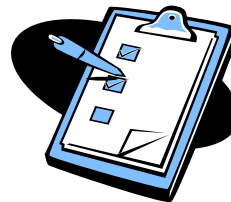
Instructions for taking medicine:

- Each dose of medicine should be taken with food or right after a snack or meal to help avoid stomach upset.
- How much to take is based on how much you weigh.
- Your team of nurses and doctors will talk with you about WHEN and How to take the medicine



"Let's Talk" Checklist:

- ☐ Take with food
- ☐ Call if stomach upset
- ☐ Call if black/red or sticky stools
- ☐ Follow-up laboratory tests discussed
- ☐ Make a schedule for making sure you take your medicine at the right time and day
- ☐ Tylenol is okay to take for pain relief or fever (do NOT take Advil or Motrin)
- ☐ If taking Naprosyn ---make sure to wear sunscreen if out in the sun



Disease Modifying Anti-Rheumatic Drugs (DMARDs)

EXAMPLES:

Generic Name:	Methotrexate	Leflunomide	Sulfasalazine
Brand Name:	RHEUMATREX®, OTREXUP™	ARAVA®	AZULFIDINE® SULFAZINE

What are DMARDs For?

DMARD's are another type of medicine used to treat arthritis. Some DMARD's are given by mouth and some are given by an injection. They take time to work, usually several weeks or months.



Things to Remember When Taking a DMARD

- **No** live virus vaccines while taking a DMARD (i.e. measles/mumps/rubella (MMR), polio by mouth, or chickenpox)
- **Get** the flu shot (**killed virus**) every year
- **Do NOT get FluMist®** nasal vaccine (live virus) when taking a DMARD
- **Get** information about what to do if you are exposed to chicken pox

When Should You Not Take Your DMARD Medicine?

Problem	What To Do
If you have a fever (temperature at or above 100.4° F)	Restart the DMARD when you have no fever for 24 hours.
If you have been exposed to/or have chickenpox, shingles or "Mono"	Do not give the DMARD and call your nurses or doctor.
If you are sick with more than a common cold, like pneumonia or strep throat	Call your nurses or doctor if you are not sure if you should give the DMARD.

If You Are Having Any of These Problems, Call Your Doctor's Office.

Biologics

EXAMPLES:

Generic Name:	Etanercept	Adalimumab	Abatacept	Infliximab
Brand Name:	ENBREL®	HUMIRA®	ORENCIA®	REMICADE®

Generic Name:	Tocilizumab	Anakinra	Canakinumab
Brand Name:	ACTEMRA®	KINERET®	ILARIS®

Biologics are a type of medicine that we use to treat arthritis. These medicines help avoid and decrease disease damage. They also decrease your chance of disability. Biologics are given by a shot or IV (intravenous).

Things to Remember When Taking a Biologic:

- **Must** have a tuberculosis (TB) test before starting a biologic
- **No** live virus vaccines while taking a biologics (i.e. measles/mumps/rubella (MMR), polio by mouth, or chickenpox)
- **Get** the flu shot (**killed virus**) every year
- **Do NOT get FluMist®** nasal vaccine when taking a biologic
- **Get** information about what to do if you are exposed to chicken pox

When Should You *Not* Take Your Biologic?

Problem	What To Do
If you have a fever (temperature at or above 100.4° F)	Restart biologic when you have no fever for 24 hours.
If you have been exposed to/or have chickenpox, shingles or "Mono"	Do not give biologic and call your nurses or doctor.
If you are sick with more than a common cold, like pneumonia or strep throat	Call your nurses or doctor if you are not sure if you should give the biologic

If You Are Having Any of These Problems, Call Your Doctor's Office.

Corticosteroids

EXAMPLES:

Generic Name:	Corticosteroids
Brand Name:	Prednisone, Prednisolone, Methylprednisolone

Corticosteroids (sometimes called "steroids") are medicines used to treat many diseases. These are not the same type of steroids used by athletes (e.g. football players) to build muscles. These are similar to hormones made in the adrenal gland. Steroids are used to control inflammation in the body. Steroids can be given by mouth or IV. Sometimes specific types of steroids can be put into joints to decrease swelling, pain and limitation of motion.

There are side effects which you should know about. Side effects happen more often when you take high doses, more than once a day, or for a long time. The side effects can be divided into early and late. **We advise you to wear a Medic-Alert Bracelet stating you are on corticosteroids.**

<p><u>Early:</u></p> <ul style="list-style-type: none"> • More hungry • Weight gain • Stomach upset • Fluid retention, sodium (salt) retention • High blood pressure (hypertension) • High blood sugar • Mood changes, sleep changes • Infection risk is higher (esp. chickenpox) • Extra hair growth • Puffy cheeks, abdomen • Acne (pimples) 	<p><u>Intervention:</u></p> <ul style="list-style-type: none"> • Make healthy food choices • Make healthy food choices • Take with food; may need medicine • Eat low salt in foods and drinks • Eat low salt in foods and drinks • May need medicine • Can get treatment if needed • Talk to your doctor/nurse • Do not shave! • Cannot stop this – often seen in 2-4 weeks • Can get treatment for this
<p><u>Late:</u></p> <ul style="list-style-type: none"> • Delayed growth (esp. high doses) • Thin bones (osteoporosis) • Clouding in the eye (cataracts) 	<p><u>Intervention:</u></p> <ul style="list-style-type: none"> • Decrease dose if possible to allow growth • Add calcium and Vitamin D to diet • Keep regular check-ups with the eye doctor

Your doctor or nurse practitioner will have a plan to reduce or discontinue steroids as soon as possible to reduce the side effects listed above.



Corticosteroids cont.

Special Precautions:

- **No** live virus vaccines while taking a steroids (i.e. measles/mumps/rubella (MMR), polio by mouth, or chickenpox)
- **Get** the flu shot (**killed virus**) every year
- **Do NOT get FluMist®** nasal vaccine (live virus) when taking steroids.
- **Get** information about what to do if you are exposed to chicken pox
- **Never stop this medicine without checking with your doctor. If you stop without checking with your doctor you could get sick or your JIA could get worse or come back.** Your body does not make the usual hormone while you are taking the steroids. Also, your body will not make the hormone quickly if you stop. You will need to have a plan with your doctor to get off the steroids slowly over a period of time.
- **Call** your nurse or doctor if you have vomiting longer than 24 hours

Dosage and schedule:

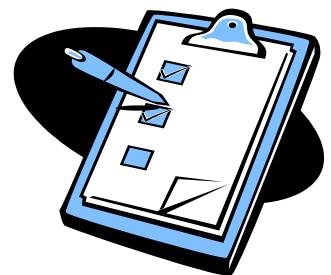
Your doctor will tell you how much steroid medicine to take.

Steroids are usually taken once a day but can be given more often. If you are taking steroids once a day, then **always** take your steroid medicine in the morning. If you are taking steroids more often, then your doctor will give you a different schedule.

Steroids started: _____
month/year

CHECK LIST FOR DISCUSSION WITH YOUR PROVIDER:

- | | |
|---------------------------------------------------------------------------------------|-----------------------------------------------|
| <input type="checkbox"/> Diet instructions | <input type="checkbox"/> Calcium supplements |
| <input type="checkbox"/> Eye exam schedule | <input type="checkbox"/> Medic-Alert Bracelet |
| <input type="checkbox"/> Plan to taper steroids or schedule for steroids over time | |
| <input type="checkbox"/> Chicken pox precautions, immunizations for chicken pox | |
| <input type="checkbox"/> Immunization status (no live virus vaccines) | |
| <input type="checkbox"/> Laboratory follow-up, especially urine glucose | |
| <input type="checkbox"/> If you have questions or concerns, call you doctor or nurse. | |



Intraarticular Steroids

EXAMPLES:

Generic Name:	Triamcinolone Hexacetonide	Triamcinolone Acetonide
Brand Name:	LEDERLON®	KENALOG®

This type medicine or “steroid” is used for joint injections.

What is a Joint Injection?

- It is a way to put steroid medicine in a joint.
- The purpose of a joint injection is to decrease swelling and pain in a joint.
- The swelling usually gets better in a few days, but the full benefit may not be seen for 2-4 weeks.
- The benefit can last a few weeks or several months. Some kids have even had benefit for years.
- Sometimes fluid is taken out of the joint to decrease swelling. This fluid may be sent for testing.



What Will the Joint Injection be Like?

- Joint injections are often done in the Rheumatology clinic or in the x-ray area. Sometimes they are done in the operating room while you are asleep. Your doctor will decide the best place for you to have the injection.
- A doctor or nurse practitioner injects the joint. Others may be there to help you keep calm or relaxed during the injection.
- Parents can be with you during the injection.
- If you are really scared or nervous, then you can often get a medicine by mouth to help you relax.
- The joint injection takes about 10 minutes.
- Usually, numbing cream is put on your skin so you don't feel the needle stick. The cream is put on about 20 minutes before the injection.
- Extra numbing medicine is often put into the joint to help numb under the skin. Patients usually say that this stings a bit, but the stinging only lasts about 10 to 30 seconds.
- Fluid is often taken out and the steroid medicine is put into the joint.
- Some patients say they feel “pressure” during the joint injection.



Intraarticular Steroids (cont.)

Possible side effects:

- A small amount of bleeding at the site is normal.
- Infection is possible but this is *Very* rare. Special safety measures are taken to help prevent this.
- Thinning of skin can happen **if** the steroid medicine leaks out of injection site or into tissues around the joint.



What Happens After the Test?

- The injection site may be a little sore after the injection.
- You should feel less stiffness after a joint injection, but this may take a few days.
- If the injection was done on a knee or ankle, this means you need to “lay low” for 24-48 hours to rest your joints.
- Call the rheumatology doctor or nurse for any questions or if you have drainage, redness, pain at the site, or you develop a fever. A fever could mean infection requiring IV antibiotics.

CHECK LIST FOR DISCUSSION:

- ☐ Joint or joints to inject
- ☐ Safety measures to make the skin “germ-free” for injection
- ☐ Numbing medicine and how to put on
- ☐ Possible side effects of injection
- ☐ Limiting activity for short time after injection
- ☐ Should I do PT after the injection?
- ☐ When to call if problems (fever, redness, drainage, or pain) occur



Vaccines

Vaccines help lower the risk of getting some infections. Vaccines are very important for people with certain medical conditions or **who take medicines** that lower the body's ability to fight infection (also called "low immune system" or "immunocompromised"). In fact, people on medicines that can lower the body's immune system may need to get special vaccines. They may also need to be checked to see if vaccines they received in the past are still working. Sometimes, vaccines stop working overtime and a "booster" shot is needed.

Pneumococcal Vaccine

If your child has a low immune system, he/she is more likely to get infections from bacteria called pneumococcus. These bacteria can cause serious infections like pneumonia and meningitis and ear infections. Your doctor may recommend one or two vaccines to help protect him/her from these bacteria. These can be given during your clinic visit in Rheumatology, or at your child's primary care provider's office.

Hepatitis B

If your child has had hepatitis B infection and has a low immune system, the virus could come back. If this happens or if you get a hepatitis B infection while having a low immune system, the infection could be very severe or deadly.

You/your child received hepatitis B vaccine when they were small to protect against this virus. In some people, the vaccine stops working overtime. If your child has a low immune system, we will do a blood test to see if your child are still protected from the virus.

If needed, we will give the Hepatitis B "booster" vaccine and later do a repeat blood test. Based on the test results, it is possible 2 more doses of a similar vaccine may be needed over the next 6 months to make sure they have protection against Hepatitis B.

Tuberculosis (TB) testing

Tuberculosis (TB) is a serious infection in your lungs. There is no vaccine for TB but there are 2 types of tests to check to see if your child has been exposed to it. This is often needed before your child can start certain medication so we can be sure they do not have the infection.

A PPD test is a skin test that is read by a doctor or a nurse 48-72 hours after it is given.

OR

Quantiferon is a blood test that can be sent for testing. The results come back in 3-4 days.

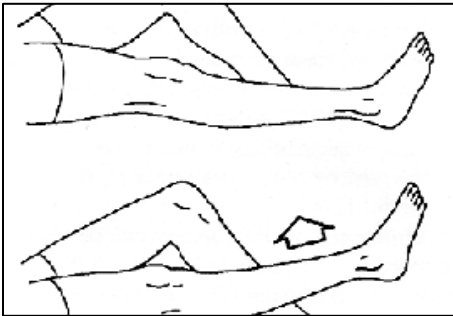
If your child needs any of these vaccines or testing, our team will give you more information about the vaccine and its safety before giving it. It is also important to remember that if your child has a low immune system, he/she should **not** receive any LIVE virus Vaccines.



Occupational Therapy and Physical Therapy

For most kids with juvenile arthritis, your provider will order occupational therapy (OT) and/or physical therapy (PT). There are many reasons to have OT or PT. Some of the reasons may be to improve joint motion, to help with pain and stiffness, to learn exercises, to have splints made, and to help make everyday activities easier to do.

Exercises are prescribed to improve how you move and to make you stronger. You usually need to do the exercises every day or sometimes more than once a day. The therapists will give you specific instructions, and these may change depending on how you are doing at various times. We will be teaching you how to do your exercises. The exercises are done at home and/or at school.



The therapists may give you “stretch bands” to help with your exercises. If you get exercises to do, your therapist will give you written directions on how to do these. Copies of the exercise sheets should be placed in your *Handbook*.



Sometimes splints or casts may be made for you; for example, for your hand or wrist. Splints help reduce inflammation and pain in the joint. The splint places the joint in a position to protect it from loss of motion and to encourage function. Some splints can be worn during activity to reduce pain and protect the joint.

The OT and PT can help you with everyday activities like self-care, play, school, or work activities. You may receive help with problems in these areas by learning to do them in a different way, or learning to use gadgets to do the activity. Special equipment or techniques should make your activities easier and faster to do. You should also need less help from others. You should be more independent!

Let's Review:

1.) Taking your medicines the way they are prescribed is important because taking too much can be harmful and not taking them as often as you should may not help you.

- ☐ True
- ☐ False

2.) The following are important if you are taking a DMARD, Biologic, or steroid (check the right answer or answers):

- ☐ Do not get any live virus vaccines
- ☐ Get the flu shot every year
- ☐ Do not take the medicine if you have a fever over 100.4 degrees
- ☐ All of the above

3.) Which medicine must be taken with food? (check the right answer or answers)

- ☐ Enbrel
- ☐ Naprosyn
- ☐ Methotrexate
- ☐ All of the above

4.) You should call your doctor or nurse if you get a fever after a joint injection.

- ☐ True
- ☐ False

5.) Examples of Biologics include which of the following medicines? (check the right answer or answers)

- ☐ Enbrel
- ☐ Naprosyn
- ☐ Methotrexate
- ☐ Humira
- ☐ Actemra

Notes

[illegible]

Chapter 4

Focus on the Family

Family Feelings and Support



WHAT YOU SHOULD EXPECT FROM US

- To talk to you and listen to your opinions or concerns
- To check in with you about stress, feelings/emotions, school issues, or social concerns
- To help find someone who can talk to you in clinic or a referral to a therapist, if needed, to help you with any difficulties you may be having



WHAT WE EXPECT FROM YOU

- Be open and honest about how you are feeling
- Let us know if you are having difficulty dealing with your JIA
- Tell us when there is stress or other difficulties in your life
- Keep appointments with therapists
- Ask questions---it's good to have lots of questions!

By now, you have been told that you have JIA. This is a chronic disease. That means it will last a long time. There may be times that you have symptoms or problems; however, there may also be times when you don't have problems. It is normal for you to have a lot of questions and many different feelings. You may feel sad, angry, afraid, guilty, frustrated, and sometimes lonely. **NO MATTER HOW YOU FEEL, IT IS OKAY TO FEEL THAT WAY.** There are no right or wrong feelings for you to have.

It may be helpful to share your feelings with a friend, parent, brother, sister, family member, or school teacher or counselor. Sometimes feelings change when you can talk them out, even though they don't change right away. Your feelings, in all likelihood, will change with time. They may become less strong or even just go away.

Several families have found it helpful to talk about their feelings and share them with others. As a way of helping other families, they offered to share their thoughts and feelings with you. The following pages have letters from parents, as well as kids with arthritis. We hope these letters are helpful to you.



A 12 year old girl with JIA

I remember a certain day in April when my life changed forever.

On this day, my family sat in our living room waiting for a call from my doctor. He would be calling us about test results and x-rays I had taken that would tell me if I had juvenile idiopathic arthritis.

That call finally came. By the expression on my mother's face, I knew the test came out positive. As I went over to my father and cried on his shoulder, the thought crossed my mind, "Why me? Did I do something wrong to deserve this?"

My doctor told my mother to take me to a rheumatologist. On the way there, my mom held my hand and told me we would get through this as a family. Since then, I learned a lot of things. I've learned how much God, family, and friends mean to me. Without them, it would be hard to get through the hardest times.

Even though having any disease is not fun, it can change your life for the better. Arthritis brought my family closer together. Even though it wasn't a good experience we got through it together, not as one individual, and we found out that even in the hardest times, we love each other as much, if not more.

I think arthritis made me stronger in my belief in God and healing diseases. Whenever I would read a section in the Bible about God healing the sick, the miracle never sunk in. But for me to be in such a bad condition and be healed, was a miracle come alive for me. This time though, it sunk into my mind and body forever.

During rough times, I also found who were my friends. My definition of a friend is someone you can trust to be there when you need them. My friends stuck up for me and helped me whenever I had flare-ups or when I wasn't feeling very well.

When you're going through any disease, you learn a lot of things – how strong you are, how much your family means to you, and who are your friends – to name just a few.

I hope the best comes to you and your family in this situation.



Parent of a 15 Year Old Girl with JIA

Having a child with arthritis and being a single parent was the hardest job ever set before me. I started keeping a daily journal of my child's illness, including information for myself and the doctor. My oldest daughter felt neglected at times, because she was being shipped to relatives when we were in the hospital. I had to make time for her, my sick child, and maintain my full-time job.

With my daughter's disease, she had very high fevers that would occur every night. Those were the times I could remember being very scared. All I could do was try to keep her comfortable and wait for the fevers to break. It is very frustrating when all you can do is watch and wait. I learned a lot of patience.

School began a month after my child became ill. She was starting junior high at a high level academic school. I knew she would be unable to attend on a regular basis. Unaware of the laws protecting children with medical disabilities, I obtained the manual, "Educational Rights for Children with Arthritis." This manual enabled me to request from the school officials the necessary requirements that my child needed in order for her to attend school. At first they were not receptive to the idea, but I would not give up. They finally cooperated and my child attended school whenever she could, and I picked up her school work when she could not attend. My daughter did excellent! At the end of the school year, she was asked to participate in their honor classes the next year.

I believed in what my daughter was capable of doing despite her disease, which helped her to believe in herself. As a result, our relationship has grown.

Father of an 8 Year Old Boy with JIA

My son was 2 1/2 years old when he was diagnosed with JIA. He was hospitalized at first and had to go through test after test, and physical therapy to straighten his bent leg. This was really hard. I remember thinking – why him, why now? He's so young. Will he walk again, will he run and how much pain will he have to go through? Will it ever end?

*The pain and suffering my son has had to endure breaks my heart, yet he never complains. He is a bright and happy 8 year old now, with many friends and interests. JIA is a part of our life – **but not our life.***



Parents of a 3 Year Old with JIA

When our son, David, was first diagnosed with arthritis, we were very upset and concerned because we did not know anything about this disease. But, the doctors were wonderful in helping us to understand everything about it. We were very afraid of how it would affect his walking because they had discovered it in his left knee. Then on one of his regular monthly visits, they discovered arthritis in his right wrist. David was given medication to take twice a day, and we performed physical therapy with him three times a day. As a result of this, his condition has improved so that he had complete mobility. His progress has gone so well, that our regular check-ups have been reduced from once a month to every three months.

Although David's prognosis is good, we still live in fear that the disease may worsen. We watch him running and playing with other children, and we have mixed feelings. Sometimes, we experience the simple joy of watching a healthy 3 year old at play. During those periods, we are very thankful that his arthritis is under control. We are also thankful for the excellent care and treatment he has received.

Then there are other times when we think we see a limp. Or we look at his knees and wonder if they look more swollen than yesterday or last week. We wonder how the disease will affect David later in his life. Will he have a full mobile life or will his participation in athletic activities be curtailed? Or, in our worse nightmare, will the arthritis flare up in a systemic problem and drastically change all of our lives?

We do not know the answers to those questions at this time. We probably will not know them for many more years. But until then, we take each day at a time with David, watching him play as any 3 year old should. And we take each day confident that, whatever may happen in the future, we will receive support and care from his care team.

8 Year Old with Polyarticular JIA

Hi, I was 8 years old when I was diagnosed with arthritis. I was worried that I might not be as good anymore, and that that no one would like me anymore. I worried that I couldn't do that much stuff, like jump rope, take gym, and other things. I thought that my brother, who also has JIA, would be mad at me because I have the same disease. I also worried that because I couldn't do things that my friends would leave me out of the fun. But I felt better when I found out that my friends understand. I know my team well because my brother had the same doctors. I like them a lot. I think if I do my exercises and take my medicine, I will be O.K. I don't like having JIA, but its O.K. because I get fun doctors.



13 Year Old with Polyarticular JIA

There are people out there that think their biggest problem is they got a bad grade, or someone didn't invite them to a birthday party. Some kids even make jokes because they don't understand how hard it is to deal with a disease like this.

I was diagnosed with polyarticular juvenile idiopathic arthritis at age 11, but had pain since I was 5. Just because I don't look sick, doesn't mean that I'm not sick. They always make fun of me because I have to miss school so much. It's so easy to judge someone on what they are wearing or how they look, you need to walk a mile in their shoes before judging them. For example, I consider myself lucky I have juvenile Arthritis and let me tell you it absolutely sucks, there are times I feel bad for myself but I need to remember that always there will be a better day ahead.

A saying people always say is to "look at the bright side" and when I thought about it how could there possibly be a bright side to this?

To tell you the truth after thinking about it, I can say because of Arthritis: I am stronger. Before I had arthritis I thought differently, I guess you could say I had a different perspective. I'm not saying that I'm always looking at the bright side of things, but I'm trying.

I know I am strong, and I have learned to understand myself better. When you are facing something hard, it's ok to be sad or angry, but think there is always someone who has it worse.

In the movie Soul Surfer, which was based on a real story, Bethany Hamilton loses her entire arm in a shark attack yet she kept surfing, don't let a bump in the road control your life.

As Bethany Hamilton said "I don't need easy, I just need possible". Don't give up, be brave and face what's coming. I believe I have the power to fight this disease!



Teen with Spondyloarthropathy

Two years ago, I was also diagnosed with a mild form of arthritis known as spondyloarthropathy, which is essentially permanent tendonitis. Though I have a mild form of arthritis, I have personally experienced the brutality of the disease by witnessing what my younger brother goes through on a daily basis.

I've seen my younger brother suffer in ways that I can't even imagine, and it is extremely hard to watch at times, but I stay positive. Since my brother's diagnosis, we have attended multiple national juvenile arthritis conferences, and have made lifelong friends at them.

The families that my family has connected with over the past years have shown us that we are not alone; they gave us hope, and have supported us when we were at our lowest of lows. Once my brother was diagnosed in 2010, I knew that I wanted to go into pediatric rheumatology.

There is currently no cure for juvenile arthritis, or arthritis in general, but I hope to change that one day; I want to put a stop to the suffering that the 300,000 children in the United States, who have arthritis, endure on a daily basis and I am more determined than ever to find a cure.

In the meantime, we have to stay hopeful. We have to stay hopeful as patients, parents, siblings, and friends. We have to stay hopeful that there will be a cure, and that these children will, one day, be pain free.



Mother of a 5 Year Old with JIA

I know it might be difficult to believe right now, but everything will be okay. We've walked in your shoes and we know full well the rollercoaster of emotions you are feeling. While the gravity of hearing this news may weigh heavily on you at this time, rest assured it will eventually fade and make way for everything else in life – school, play dates, sports, bumps and bruises.

Jessica is a warrior, full of life, energy, curiosity, confidence, determination, spunk, and beauty. She was diagnosed with JIA at just 20 months old and is now 5, leading the active lifestyle of a child.

If we can offer any words of encouragement, it would be to believe in your child, love them and empower them to live life to their fullest potential! Do not let Juvenile Arthritis define your child. A blood test might tell you about an illness, but it certainly cannot measure one's resiliency, strength, courage, humility, compassion, and beauty. Your child is more than a test!

You and your child are not alone. There are people just like yourselves willing to offer support, you just have to look. While your family and friends may not know the depth of what you are feeling, don't be afraid to let them in. Your team of doctors who know how to treat this disease can also provide a wealth of support and guidance.

Believe! Believe in yourself! Believe in your child! Believe in your medical team! There will be good days and bad days. There will be days when simply getting out of bed is a challenge or when frustration will go into overload as everyday tasks take that much longer to do. We promise you though; there will be many good days too. Days filled with proud smiles as your child accomplishes something they have worked so hard to achieve and days where they will be pain free doing the things they didn't think were possible days prior. Everyone experiences struggles in their life. There will be times when your child cannot do something, but believe and don't ever lose hope that one day it will be possible!

Your child may have Juvenile Arthritis, but Juvenile Arthritis doesn't have them. Never underestimate your child's abilities and the power they have to make a difference!

**MAKE A
DIFFERENCE**

Mother of a 21 Year Old with JIA

I remember when our daughter entered this world. She was a tiny thing, weighing in at under 5 pounds. She was welcomed home by her older brother of three years and a Beagle dog. She was a challenging baby, colicky for almost 6 months. She was a busy toddler, walking, running, doing all the things that toddlers learn to do. Little did I know, in just a few months, our family would begin a great battle with a not so well-known childhood disease.

One day, my daughter woke up with a rash, covering the upper part of her body. I took her to the doctor, and he said that she had scarlet fever, gave us some medicine and sent us on our way. Over the next two or three days, the rash got worse, and she began to run very high fevers. The fevers were so high that we rushed her to the hospital. After about seven days of testing and elimination of leukemia, spinal meningitis, and other serious diseases, the doctor said, "Your daughter has juvenile idiopathic arthritis (JIA)." How can a baby have arthritis? It's an old people's disease? We were very scared, but grateful, but at least knew what was wrong. However, over the next 10-12 years, I wasn't always so grateful. I can't begin to explain what my daughter went through. I felt so useless for her, so tired.

My husband was the one who made our livelihood, so I became the primary caretaker. I began to educate myself about JIA, contacting the Arthritis Foundation, reading all I could. For our daughter, this disease affected her whole body. This disease is a personal one, not affecting everyone the same. So what happens to one does not mean it will happen to you.

Our daughter at times had to be more dependent on us, often needing help with day-to-day activities. The pain comes and goes for her (and me). I can honestly say I hate this disease, for it has changed many things for my daughter. Believe me, if I could have changed anything for my daughter, it would be this disease. However, I can tell you that I thank God for her every day as she has taught me so much. I have met many people along this journey and for that I am very grateful.

Our daughter will be 21 soon. She graduated valedictorian of her high school class and is now in college. Her life is better, not pain-free yet, but she is not dependent on us anymore. As I look back over those years of fighting the JIA, I thank God for our doctor who was always there for us and for family and friends who helped when they could. What advice do I have for moms whose children might face this disease? Do the best you can and know that it is OK to cry, scream, and be afraid.

These are all feelings that are part of being a parent whether you have a child with a disease or not.



Mother of a Daughter with JIA

Megan was diagnosed with Poly JIA at the age of 21 months. We realized something was wrong when she was 18 months old, not walking, and strongly disliking physical therapy aimed at helping her walk. Babies are chubby, so I never even noticed the swelling in her wrists, knees, ankles, fingers, and toes.

When we were first diagnosed, I wish someone had told me "There are families all over the world sharing your same struggles. Here is a list of online and in-person support groups so you can talk to another parent who shares your story." It took me almost a year to find such a thing on my own, and I hope no parent has to go through this alone.

The parents and patients I have had the pleasure of "meeting" though online groups have been amazing. They all understand the journey, although no one has the exact same experiences. The differences we have among our members allows a very well-rounded list of opinions, suggestions, and advice whenever a question arises. This diverse feedback truly allows a parent to make the most informed decisions in partnership with their doctors.

Living with JIA is truly like riding a rollercoaster, with highs when you feel hopeful to lows when things are going every way but right.

Thankfully, we are in a hopeful place right now, but I vividly remember the lows, and don't wish for anyone to do it alone.



Mother of Daughter with JIA

"After the Snowball Hits"

"Is this like asthma?" I asked. My husband knew what I meant. He used to be terrified every time I wheezed and would race to bring me an inhaler while I laughed at his comical expression of fear. I've had asthma my whole life and thankfully it's usually no big deal. It was new to him though and it scared him badly. Here we were now, waiting for the elevator at Boston Children's Hospital, our youngest, just a little toddler, newly diagnosed with Juvenile Arthritis. Asthma was the only lifelong illness I could compare it to. I was hoping with all of my heart and soul that this was like my version of asthma, just an annoying part of life.

Having my child diagnosed with such a serious, unfamiliar chronic illness was like stepping off of the sidewalk and finding nothing but air underneath me. Somehow I was still standing, still walking but it was completely nonsensical. It took time to process. It took fear and worry and grief for the loss of the imagined life she would lead. And as time passed our new normal created itself. There were doctors and therapy and testing and medicines, but there was also school and friends and beach days and holidays. My child was growing everyday with this disease and every day she was living her life.

Katherine is ten now and amazing. She loves school and piano. She's artistic and smart. Her friends greet her with hugs and teachers remark on her kindness. Katherine's arthritis is challenging. It seems smarter than us most of the time. Unfortunately for Katherine JIA is a very big, life altering deal. It is also just a part of her life, a part that is helping her grow up empathetic, caring, and remarkably strong.

Raising a child with Juvenile Arthritis is challenging. It can be scary and isolating and sad. The disease loves to keep you on your toes, throwing new problems at you as soon as you control the current ones. It steals time and energy and so many moments of childhood. Reach out. Support is there.

Ask your rheumatologist, connect through Facebook, call the Arthritis Foundation. Ask questions, research, read. Know that life has just hit you with a big icy snowball and is watching and waiting to see what you do in return. Love your child, listen to her, listen to her care team and then take her and go play.



Eighteen Year Old with JIA

I was diagnosed with juvenile arthritis when I was 12, just a few days before Christmas. Since then, my life has been a tornado of flares, pain, and medications. But that's not all it's been; it's been hope, too.

I met other kids who had arthritis when I was 15, and it was the most amazing feeling in the world. There were others just like me! They understood exactly what I was feeling and going through! They had helpful tips and I was even able to give them some advice. I hadn't known any other kids with arthritis before. Sure, I knew they had to exist, because my pediatric rheumatologist was always swamped with patients, but I'd never met them.

There is hope. There is always hope, no matter how bad things look. We're fighters, and fighters always come out on top, because we learn from every experience.

When I was first diagnosed with JA, I was nearly eaten away by my loneliness. Don't. You, reading this, are now part of a family that is 300,000 strong; You have 299,999 brothers and sisters who understand you completely. We will never let you go through anything alone; we will always be there.

17 Year Old Girl with JIA

Hi, I'm a 17 1/2 year old and I have JIA. When I found out that I had JIA, I was 8 years old. I was also confused, angry, scared, all at the same time. Sure, I'd heard of arthritis, but, like most people, I thought that arthritis was something that only "old people" got, not people my age. I know it can be hard to accept, but just because you have arthritis like me doesn't mean that life is over.

There may be a few changes, like you might have therapy. But just because there may be a few changes in your life, doesn't mean you have to give up your hobbies. As a matter of fact, my hobbies haven't changed much since I was 8. I still love reading, writing, listening to music and playing, collecting and sewing for my dolls. But playing with and sewing for my dolls is wonderful hand therapy. Also a doll can be a comfort when you're feeling sad, angry or scared.

But keep your mind and body active, and remember --you can do anything if you put your mind to it. Never, ever give up!



Parents of Son with Polyarticular JIA

Hello new family. I'm sorry that we are becoming acquainted in this way but please know that you are not alone. We understand what you are feeling.

Our son Maddox was diagnosed at 17 months with severe polyarticular JIA and uveitis. You may be feeling relieved that you finally have a diagnosis after so many initial doctor's visits. Or you may be feeling confused about why this is happening to your child, or angry, or guilty, or worried for the future, or sad, helpless, scared, alone, resentful... we get it. We've felt all of those before and continue to occasionally rotate through those feelings... but we are also ok now.

We feel grateful, happy for the good days, proud at different developmental stages and milestones, impressed with the incredible amount of empathy and emotional intelligence our children seem to have with a chronic illness. This disease is hard- it's full of ups and downs and the moment you get to a good place and start to let your guard down you inevitably seem to hit a roadblock. It's ok though. These hardships are defining your child's character and your child will become stronger and wiser. You will get through this...and when you think you can't - pick this book up or talk to another parent in a support group.

You've made it through every rough day up to today successfully. You've got to keep moving ahead. Trust your intuition if something doesn't seem right and be your child's advocate. Most importantly, reach out to someone that understands when you need help. You and your child will be ok!



Chapter 5

School Issues



WHAT YOU SHOULD EXPECT FROM US

- To talk with the school staff and share medical information at your request
- To work with you and school staff to help solve any school problems related to JIA
- To help with completing and turning in any necessary school medical forms or letters at your request
- To answer your questions



WHAT WE EXPECT FROM YOU

- Tell us about any school problems or concerns you may be having
- Share information about your JIA with school staff
- To begin any necessary paperwork when appropriate
- Ask questions

Communication with the School

School is an important part of your life. In fact, going to school is the most important job for you. It is important that school be as positive as possible. This is especially true if you have arthritis. Perhaps it is even more important. At times, arthritis can affect activities at school. Now and then, special changes need to be made. All members of your team (you, your parents, health care team, and the school staff) will work together to make school a positive experience for you.

The key to making things work at school is good communication between you, your team and your school staff. Most schools are very willing to make necessary changes in class programs. It is very helpful for you and your parents to meet with the teacher (or the principal, school nurse, and/or physical education teacher) to talk about your arthritis. Schools will need information about your arthritis, medicines, and any special needs.

Your health care team can help you with information for the school. Sometimes, they can write a letter or just talk with the school on the phone. Your health care team can talk or share information with the school about your arthritis history and needs. School nurses can be an excellent resource to help other school staff understand medical information. (Remember, you or your parents will need to give “written consent” for your health care team to share information with the school). The Arthritis Society or The Arthritis Foundation, websites also have helpful information, for teachers and schools.



You and your parents know the symptoms (like joint pain or stiffness) of your arthritis and how you are feeling about coping with everything. You also know about your medicines and therapies needed every day to manage your arthritis. The school will need to know about these daily activities too. It is important for the school to understand that arthritis can change from day to day. Sometimes, the arthritis may even change from morning to afternoon, or even hour to hour.

As you plan your school activities, think about common problems you might have at school (such as problems with stiffness, being tired, having pain, or problems moving). Try to think not only about how you are doing now, but to think about future concerns. Think about planned absences from school (appointments) or even unplanned absences (flares of disease, special tests, procedures, or side effects of medicine). It is important to talk to your teachers before the beginning of each school year. You **cannot** assume that information gets passed on from year to year.

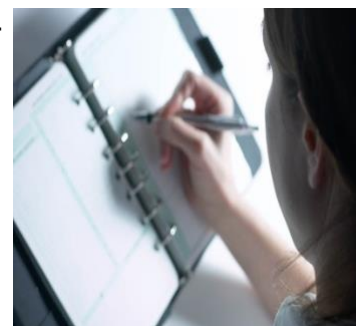


The key is to discuss things before they occur so you can have a positive school year!



Meeting School Needs

The first step in meeting your needs is to list possible challenges or problems you might have at school. One of the best ways to decide what might be a problem is to "walk through" your daily schedule at school. Think about your school routine by checking classroom setup, your desk, bathrooms, the cafeteria, library, gym, or the playground. The types of possible problems for a student with arthritis can occur in several different areas. Most kids with arthritis have only a few areas of concern. The following sections list several areas and possible ways to help for each area.



Common Problem Areas	<u>Things That May Help</u>
Problems Moving	<ul style="list-style-type: none"> • Arrange to leave class a few minutes early or to arrive five minutes late. • Ask the school to keep classes close together so you do not have to walk long distances. • Have one of your friends walk with you during class changes. • Arrange for help getting on/off the bus. • Arrange for help with safety drills. • Arrange for shortest time possible to ride on the bus. This will give you more time for bathing, dressing, breakfast, exercises, etc. in the morning. • Make special plans for gym class or with the P.E. teacher to change activities (swimming, scorekeeper, coach, timer, self-adjusted activities, etc.). • Make plans ahead of time, if necessary, during field trips, emergency drills, or special class activities.
Stiffness	<ul style="list-style-type: none"> • Talk with the teacher to let you move around the class now and then (hand out or collect papers, erase chalkboards, etc.). • Talk with the teacher to let you sit in the back, or to one side of the class so you can stand without being noticed (this may not work if you have eye problems). • Arrange for late arrival to school if needed. • Remember to keep your legs straight whenever possible. • If you have knee or hip problems, then do not sit with your legs "criss-cross." • Arrange to use a warm rice pack or wrap at school.

Common Problem Areas	<u>Things That May Help</u>
carrying books, lunch trays, or other items	<ul style="list-style-type: none"> • Ask for two sets of books – one to keep at home and one for school. • Check if there is an electronic form of books available. • Use a backpack if you do not have shoulder problems. • Have a friend help carry lunch trays or heavy items. • Get an elevator pass/key if possible. • Ask your teacher if you can store larger items in the classroom.
Difficulty writing, opening lockers, or toileting	<ul style="list-style-type: none"> • Try pencil or pen build-ups. You can get these from the occupational therapist. • Try felt tip pens, as they require less effort to use. • Get extra time to complete tests (i.e., SAT, proficiency) or time to stretch and stand. You must ask ahead of time in writing. Often you need to ask a <u>long time</u> before the planned test (You must have testing accommodations or adjustments written in an IEP or 504 Plan). • Ask permission to have shorter homework assignments, to type assignments or to get notes from a classmate. • Ask for special lock or handles on locker.
Fatigue (Being tired)	<ul style="list-style-type: none"> • Arrange for a rest period during the day or after school. • Make arrangements for late arrival or early dismissal if you feel this might be helpful.
Needing medicine at school	<ul style="list-style-type: none"> • Sign the permission slips for school. • Get a doctor's order for medicine to be given at school. • Arrange to take medications at specific times (after lunch or with a snack). • Talk about the possible side effects of your medicine with certain school staff [the school nurse and your teacher(s)].
Difficulty telling classmates about your arthritis	<ul style="list-style-type: none"> • Take part in school activities and community activities. • Take part in extra activities, like sporting events, youth clubs, and school clubs. • Help your classmates learn about arthritis, medicines, or other things you might need. • If you have them, decorate your splints. • Have a special "buddy" at school or to be part of a support group or to talk with a counselor if necessary. • Share with your friends and classmates how your arthritis makes you feel and how the medicines affect you.

Meeting School Needs

There are many ways to meet your special needs at school. **None** of the previously mentioned concerns or problems should stop you from attending school. You will need to work with your parents and health care team to decide if it is best for you to have a formal or informal plan to meet your needs. An informal plan would be through phone calls, notes, or just talking with school staff. A formal plan involves many people helping to determine and arrange ways to meet your needs.



When deciding to use an informal or formal method, it is helpful to think about the school's role in the approach or solution. If the solutions are simple and easy, then informal (a letter or talking to the school) usually works. If solutions are more involved, then a formal approach may be needed. **Remember**, each school will view solutions differently. The key is to work with the school about your needs and their ability to meet them.

Sending a letter to the school from you or your doctor may be enough. Drafting a letter to the school may be something you want to discuss with a member of your health care team.

The Education Act – Regulation 181/98

If your illness affects your ability to learn, benefit from, or perform academic tasks, then the school board is required by law (The Education Act, Regulation 181/98) to provide the necessary adjustments and/or services so you fully benefit from your education.

Identifying your Child: IEP and IPRC

Regulation 181/98 requires that all school boards set up an Identification Placement and Review Committee (IPRC). The IPRC decides on areas of a student's exceptionality, appropriate placement for the student and reviews the identification and placement at least once in each school year.

An Individualized Education Plan (IEP), by law, must be developed for every eligible child. IEP's are developed by the student, parents, teachers, and other specialists (such as members of your health care team or other school staff). The IEP must be updated every year. Special needs of your child should be included in the IEP such as: OT or PT, use of a computer or typewriter, special transportation, or having all classes on one floor. Some children may not need the formal IEP process.



<http://www.edu.gov.on.ca/eng/general/elemsec/speced/individu.html>



Some Practical Strategies to Consider

You may have times that you have to miss school because of your arthritis. You, your parents and health care team will need to work with the school to determine the amount of homework that is suitable when you have flares of your arthritis.

- List your assignments. Decide which ones are most important. When you are tired or have less energy, you may not be able to make up all missed work. Break down larger projects into smaller tasks. Pace yourself to complete the project.
- You may need to have your teachers shorten your assignments when your arthritis is flared or you are having more symptoms. For example, in math or writing assignment, limit the number of practice problems or writing. Ask for power point lectures or talks to be emailed to you.
- Ask your teacher to provide computer notes, recordings of lectures or get notes from a classmate when you are absent from school.
- Request permission to replace written assignment with audio recorded work. This can be especially helpful if you have active arthritis in your hands or wrists. There are text programs such as “Dragon Speak” (around \$100) that may be helpful. “Google Chrome” also has free apps with voice-to-text tasks. You can also ask for a scribe, which is a person to help you write on tests and class work.
- If appropriate, talk with your teacher about Pass/Fail rather than a letter grade.
- Talk with your teacher about adapting writing assignments to your situation. Write about your medical condition or experience. This can often be an interesting assignment.
- Make sure you understand from your teacher what you must complete in order to receive credit or pass the class.
- Discuss a plan with your teacher that includes assignments, due dates, rewards and consequences.
- Get a “study buddy” to work with you in problem subject areas during study hall or after school.
- Ask your teacher for a study packet of core concepts to complete while absent.
- Ask your parents to help you with your goals.



Let's Review:

1.) What are three things you could do if you are stiff or having problems moving around at school?

2.) You are not allowed to make special plans for your school work when your arthritis is flared or you are having more symptoms.

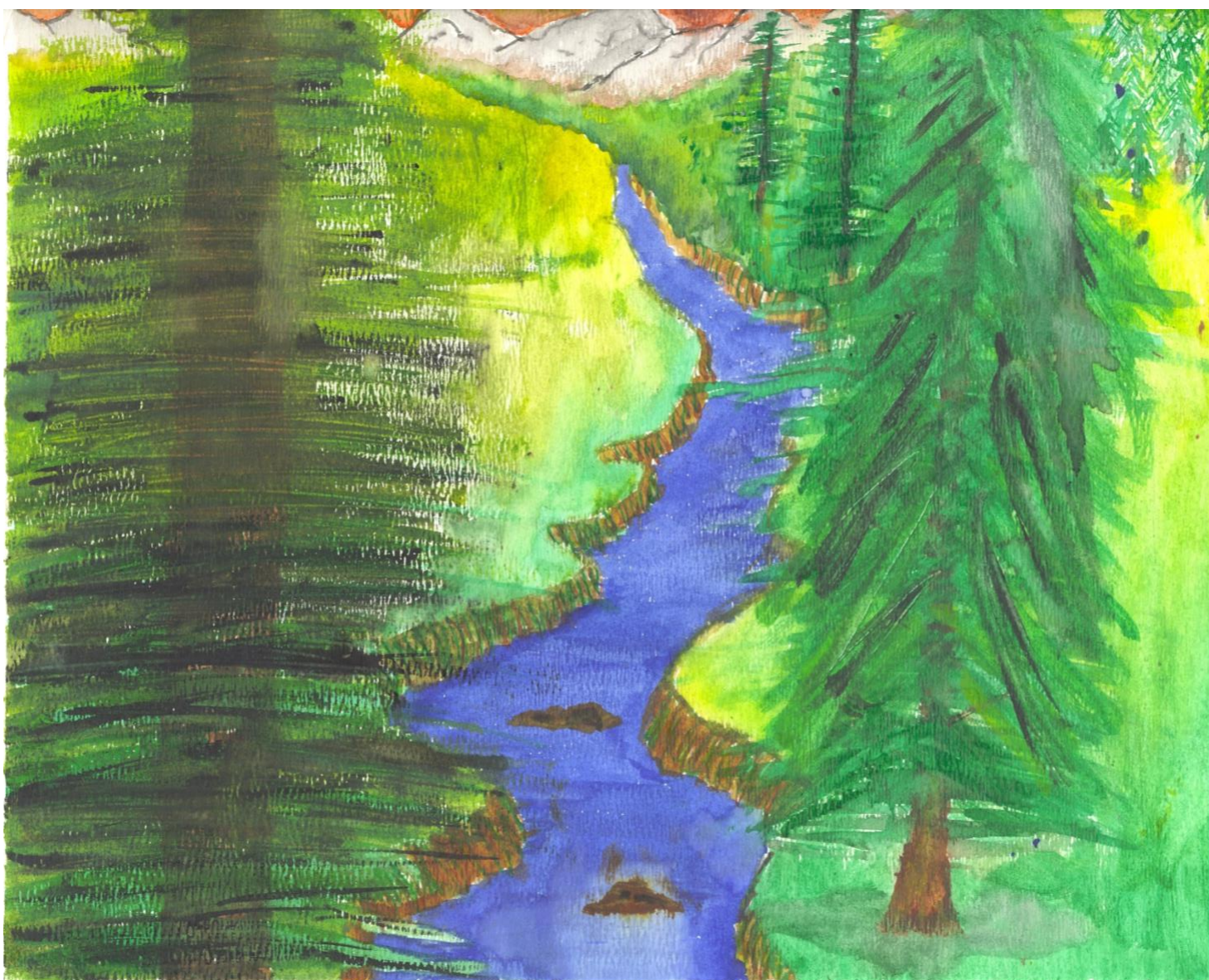
- ☐ True
- ☐ False

Notes

[illegible]

Chapter 6

Financial Resources



WHAT YOU SHOULD EXPECT FROM US

- Information about available resources
- Help with finding appropriate resources at your request
- Help with completing and turning in paperwork at your request

WHAT WE EXPECT FROM YOU

- Tell us about any financial concerns you have
- To begin the paperwork or application process when appropriate
- Ask questions

The care and treatment for JIA or any chronic illness can be costly. This can be hard for families. It is important that you know about the resources or support to help you follow your healthcare plan. We want to help you with any cost concerns so that you can focus on staying healthy and taking care of your arthritis. The direct medical costs for professional services (e.g. massage, orthotics, private physiotherapy) can be quite high. Often these are well covered by a family's health insurance plan.



Insurance

All insurance companies are not the same and will cover or pay for items differently. You will need to check with your insurance about what and how much they cover for certain parts of your care. It is always helpful to check on coverage **before** services occur. For example, some insurance companies require a medical referral/prescription for services such as massage therapy, orthotics or physical and occupational therapy.

Pre-Authorization

Sometimes it will be required to get prior authorization (permission) from the insurance company for certain medicines. If a problem arises and the insurance company refuses to pay for a medicine or a part of your care---DON'T GIVE UP! Call your team and someone will help you. There are other supports that can help to pay for medications including government programs (OHIP+, Trillium, NIHB) and even patient support programs.

The insurance company may require that some medicines, especially injections, are ordered through a special pharmacy. If you know this is the case with your insurance, then please let us know when we order the medicine.

OHIP+ - starting in January 2018, anyone 24 years or younger will be able to get their prescription medications free. Coverage will be automatic with no up-front costs. Some medications will still require a special approval process (for example, “biologics”).

<https://www.ontario.ca/page/learn-about-ohip-plus>

Ontario – The Trillium Drug Program:

<https://www.ontario.ca/page/get-help-high-prescription-drug-costs>

Your hospital may have extra financial support programs which you may find helpful. Feel free to ask your team for any information. Be sure to ask the team about any medicine assistance programs that may be helpful to you.

Ask your team about possible college or school scholarships or vocational programs that might be possible for kids with JIA. These can change from year to year.

Let’s Review:

1.) What resources are available to help with financial concerns?
(check the right answer or answers)

- ☐ Medicine assistance programs
- ☐ Insurance providers
- ☐ Hospital financial programs
- ☐ State programs
- ☐ All of the above

Notes

[illegible]

Chapter 7

Managing At Home



Managing At Home

You and your family will have to learn to manage your arthritis at home and school. There are day-to-day issues that will come up and you will need to make decisions or need to talk with someone. This is called **self-management**. This means you can take charge of your health and arthritis. You can set goals and achieve them! It does not mean you do it all by yourself. Over time, you will learn about the arthritis and resources to help you make good decisions about what you need to do.

Studies tell us with good self-management you can decrease:

- Symptoms of arthritis
- Flares of arthritis
- School absences
- Visits to the doctor

In the following pages, we will discuss helpful hints for:

- Joint pain or stiffness
- Pain relief measures
- Heat and cold measures
- Pain and stress
- Relaxation techniques
- Exercise or splint time
- Tips for taking medicine
- Getting prescriptions and lab tests
- Planning for your check-up with your health care team
- When to call the Rheumatology office



Let's Talk About Joint Pain or Stiffness



Pain is your body's alarm system. When part of your body is irritated or injured, nerves in that area send signals. The nerves act like telephone wires and send signals to your brain where they are recognized as pain. Pain "tells" you that you need to do something. For example, if you touch a hot stove, the pain signal makes you pull away your hand to prevent further injury.

Long-lasting pain (chronic) pain, like the pain of arthritis, is a little different. Chronic pain is also an alarm. Chronic pain often needs different ways to control it. Controlling this type of pain is important since it can interrupt your life.

Pain control in arthritis can affect the outcome of your disease. Arthritis pain can be caused by:

- inflammation, the process that causes the swelling in your joints
- damage to tissues caused by the disease process
- muscle strain caused by overworked muscles trying to protect your joints from painful movements

Everyone's pain is different. People react differently to pain for many reasons. Pain can be made worse by physical, emotional, or social reasons. Some examples might include fatigue, stress, depression, fears, attitude, or anxiety.


Pain can be managed. There are many things you can do to help control pain. Your mind plays an important role in how you feel and how you respond to pain and illness. It is important to learn how to help control pain. Treatment of pain often includes:

- medicines
- exercise and joint safety
- rest and/or watching your activities
- comfort measures
- decreasing stress
- cognitive behavioral therapy

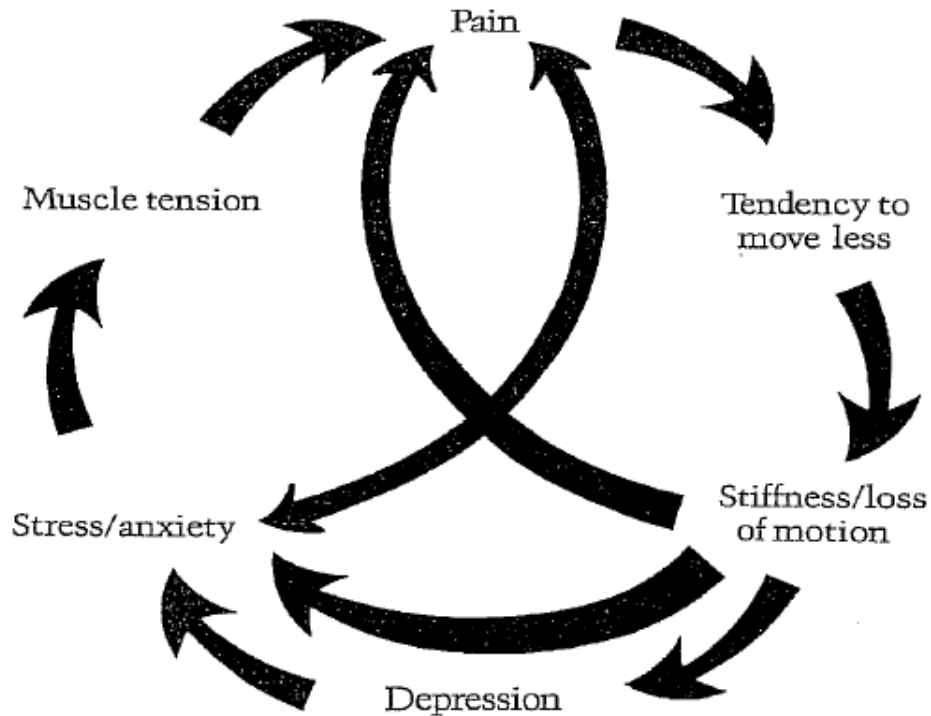
Sometimes your provider or team may send you or your child to a pain management team. This is a team that has special training and additional skills in managing pain. This team may often have doctors, nurses, psychologists, and even exercise therapists. Your rheumatology team will decide if you need to see the pain management team.

What Do I Do For Pain And Stiffness?

There is a lot you can do for pain and stiffness. Be sure to keep a positive attitude and make a pain management plan! Don't hesitate to ask for help when you need it. Try to keep track of what methods work best for you. And be sure to share your successes with your family, friends, and rheumatology team!

- Medicine can be used to help pain.
 - In most cases it is okay to take Tylenol  ® Be sure to check with your provider.
 - Do not take other pain relievers without asking your provider.
 - Do not take anyone else's pain medicines!
 - Sometimes you may need a different or stronger medicine. You will need to talk with your provider about this.
- Exercises can help with pain.
 - Be sure to talk with your physical or occupational therapist
 - *Gentle* stretching can help
 - Range of motion exercises can help
- Comfort measure or heat or ice can help with pain.
 - Warm baths or showers can help. This can help relax your muscles and decrease pain in the joints.
 - Microwave hot pack
 - Creams for heat/pain relief
 - Use an electric blanket when sleeping
 - Ice or cold pack can help with pain
- Decreasing stress or relaxing
 - Positive thinking
 - Light massage
 - Meditation
 - Listening to music or watching TV –this may help take your mind off of the pain

Pain-Stress Cycle



When moving a body part leads to pain, there is a tendency to tighten muscles and to stop moving that joint. Muscle spasms can occur, which can further tighten muscles and cause pain. Continued disuse of a joint may cause contracture (shortening) of muscles and ligaments, thus making less movement possible. This loss of motion can lead to depression and stress, which increases muscle tension and causes more pain. The additional pain can increase anxiety. And more anxiety = more tension = more pain ... and so on through the cycle.

Activities such as stress management techniques and pain relief measures can break this cycle and reduce pain and stress.

Relaxation Techniques

Once you become aware of stress, it is time to relax! Relaxation helps rest your mind and body. It can also decrease muscle tension and can help control pain. Relaxation can also provide you with more energy. Some types of relaxation can help you sleep if done right at bedtime.



There are many ways to relax. Try out different methods until you find one that works for you. Learning to relax takes time and practice. To get the best results, try to relax every day.

Below is a list of some common ways to relax. Some can be done anytime a person is having signs of stress; others need to be done in a quiet area, away from noise, people, and other distractions.

Quick Methods

Quick methods can be done anywhere and only take a few minutes. They can be helpful for young kids too.

Deep breathing. Sit or stand (using good posture) and place your hands on your stomach and chest. Breathe in slowly and deeply through your nose. Let your stomach move out as much as possible. Hold your breath in for a few seconds and then let it out slowly through your mouth. Your hands on your stomach should move out and then in as you breath in and out. (If you become dizzy, that's a signal you are breathing too fast).



Tense-Relax. A lot of stress can be focused on certain parts of the body such as the forehead, neck, or shoulders. Simply making these areas tight and then relaxing these areas can help the whole body relax. For a tense forehead, lift and then lower your eyebrows several times.

Rolls. If you do **not** have severe arthritis in the neck or shoulder areas, you can do head rolls and shoulder rolls. Gently roll your head to the left. Then return to center.



Then roll to back. Then return to center. Then roll to the right. Now shrug your shoulders as if you are trying to touch your ears. Move your

shoulders back; then drop them slowly. Move them up, back, down, and around. Move them forward and then backward, keeping your arms limp. (It's best to have your eyes open if you do the head roll standing up to keep your balance).

Rag-doll. The rag-doll stretch is good for the whole body. Stand with your feet shoulder-width apart. Raise your arms over your head and put your fingers together. Turn your palms up and stretch, trying to reach the ceiling. Rise on your toes and stretch. Holding your arms and hands in this position, lean to one side until you feel the stretch; hold for 5 seconds. Then lean to the other side, feel the stretch and hold. Now reach, lean forward, and hold. Then go limp like a rag-doll and just hang toward the floor, letting all your muscles loosen. Bend your knees as you straighten up to ease any strain on your lower back. This can also be done while sitting: just let your head hang forward, your arms dangle loosely, and your legs go limp like spaghetti.



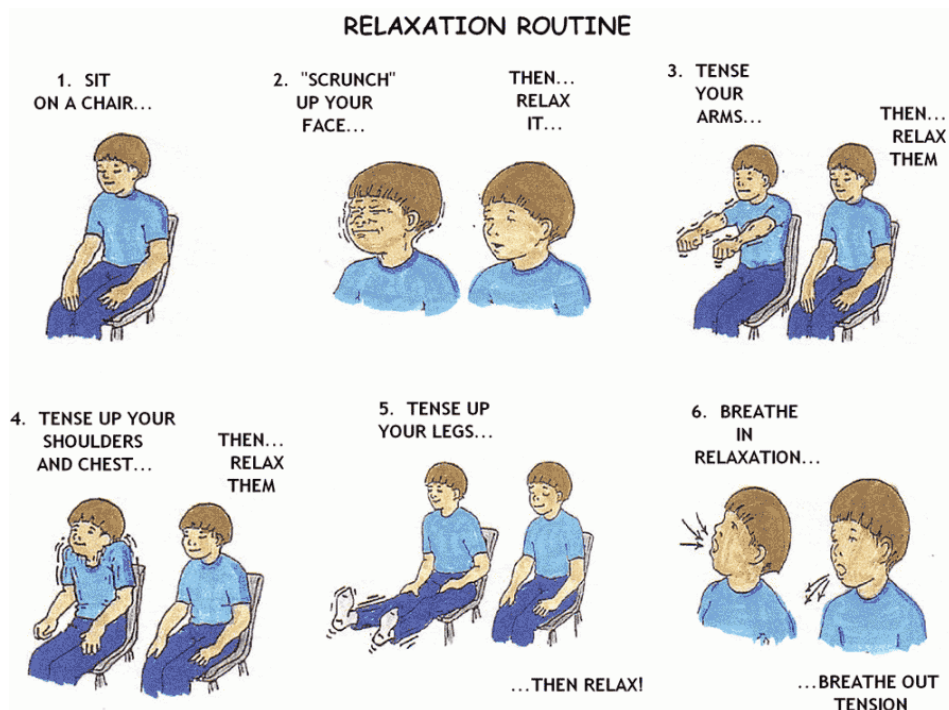
Relaxation Techniques cont.

Other Techniques

Jacobson's Progressive Relaxation. This is a three step technique: (1) tighten a muscle (any muscle) and notice how it feels; (2) let go of the tightness and pay attention to that feeling; and (3) concentrate on the difference between the two sensations. This exercise can be done while sitting or lying down, and only takes about 15 minutes. Here's how:

Make a fist for a few seconds and notice how it feels. You may feel tightness in your hand, wrist, and lower arm. Hold the tightness for a few seconds. Then let go of your hand, open your fist, and let the tightness slip away. Notice the difference between how your hand felt when tight and how it felt when you let go. Did your hand tingle or feel warm when relaxed? Did the throbbing you felt while you made the fist disappear when you relaxed? This tightening and relaxing can be done for different muscle groups in the body.

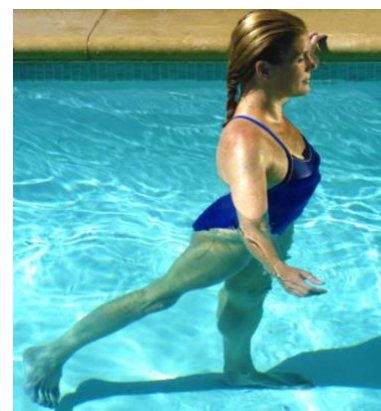
You can start with your hands and then move to other muscles. Or you can move from head-to-toe, tightening and relaxing the muscles in the face, shoulders, arms, chest, back, stomach, legs, and feet. Or you can do it toe-to-head.



Exercise or Splint Time

Exercises can be a major part of the treatment for different types of arthritis. Remembering to do your exercises can be hard sometimes. Following are helpful hints for doing exercises or wearing splints.

- Set a goal for doing your exercises (there are goal sheets or action plans in Chapter 8)
- Set a reminder on your cell phone or watch to do your exercises
- Make the time as fun as possible
- Choose where you are going to do your exercises (e.g., in your room, in the bathtub, watching TV)
- Choose the order for doing different exercises (hands/wrists exercises first, then knees) or the order for putting on splints
- Do your exercises to music
- Get other family members to do your exercises with you
- Take pictures or even videotape your exercises; then you can watch yourself and show your friends and therapist.
- If you have splints—decorate them! (color straps like zebras, stickers—what every you want!)
- Make a chart and mark off each time you do your exercises or wear splints



Try to make things as fun as possible. Your therapist may also have some creative ideas. Sometimes it is helpful to make a chart like this one:

	S	M	T	W	T	F	S
Biking	♪☺♥	v	♥♥♥♥	☀☺♪	☺	♪☀♥	☺♪
Quads	v☀	v♥☺		♥☺	♪♥	♥♥	

Tips for Taking Medicine

Taking your medicine is also a part of self-management. Taking your medicine is important. Studies have shown that patients who do not take their medicine have more flares of their arthritis. Many medicines are taken once or twice a day. Some medicines need to be given by shot or even by IV at the hospital or in an outpatient area.



“Adherence” means how well you take your medicine and follow your treatment plan. We know that you are busy with school, work, sports, or other activities. It can be easy to “forget” or “miss” a dose of your medicine or to “forget” an appointment. In fact, everybody forgets now and then.

As you get older, it is important for you to learn about your medicines. You will need to learn the names of medicines, what they look like, how often you take them, why you are taking them, and side-effects. Talk with your health care team if you have trouble remembering or are having problems with your medicines.

Following are some hints that may help you remember to take your medicine:



- Set an alarm on your cell phone or watch as a reminder to take medicine
- Look up websites that can send you a reminder text message or email alert (www.mymedschedule.com)
- Put your medicines where you can see them (next to your toothbrush or in the kitchen)
- Make taking your medicine a goal and part of your daily schedule (there are goal sheets or action plans in Chapter 8)
- Leave yourself a note or reminder
- Keep a medicine journal or chart and check off when you take each dose (there are charts in Chapter 8 of the Handbook)
- Stay organized—use pill boxes and count out your medicine for the whole week
- Ask for help if you need it!

More Helpful Hints for Taking Medicine

Here are a few more helpful hints. They may help you remember to take your medications and to become more independent in managing your chronic condition/disease.

There are several apps available to help with taking meds and managing refills. There is also an app to help with fitness and managing food intake.



- ◇ **MyMedSchedule:** allows you to input all medications and treatments and create reminders via text or email. Medications appear in actual color picture form.
- ◇ **Mango Health Medication:** allows you to input medications and time to send alerts. You can earn “cash” toward the charity of your choice when you take your medication.
- ◇ **Walgreens and CVS:** allows you to request refills for all your medications either through your medication list or by scanning the sticker on medication. Let’s you input day/time you want to pick up the medication and the pharmacy location. Check if your pharmacy has an app.
- ◇ **MyFitnessPal:** allows you to input your daily calorie needs and track foods you eat; a sophisticated food journal that you can share with others via facebook or email

Prescriptions/Lab Test Results

You need to ask for prescriptions or medicine refills at the time of your clinic visit. You can always check with the pharmacy before the visit to find out the number of refills you have left. If you need to call the office for a refill, please have the following information available:

- Name of the medicine
- Amount you take and how often
- Pharmacy phone number



Lab test results can also be reviewed at the time of your clinic visit. Sometimes the team may ask you to call after your visit to discuss the results. Usually, someone will take your name and number and the nurse or doctor will return your call. Some places have MyChart or other program to send message to your provider and see your lab results. You must sign up for this but is a good way to connect with your health care team.

Pre-Visit/Visit Planning

It is important to be ready for your visit with your health care team. Try to plan your needs ahead of time for the visit (i.e. OT, PT, nutrition). If you are having special problems (i.e. disease flare, school problems) or you have concerns (i.e. insurance), then try to inform the rheumatology staff **before** the visit.

It may also be helpful to write down things you want to talk about at the visit. There are several tools in Chapter 8 to help you plan for your visit and remember what was talked about at your visit.

At the end of each clinic visit, your provider and team will talk with you about plans for your medicine, lab tests, or other instructions for managing your arthritis. You will also be given instructions for scheduling your follow-up appointment.

When to call the Rheumatology Office

You should call your provider or health care team if you are unsure about a symptom, your medicine or have general questions that need answered.

Specific times when you should contact your provider or team are:



- If you are on steroids, DMARD's, or biologics, and **are exposed to chicken pox** or **develop Shingles** call right away. You may need a special shot or special antibiotic.
- If you are on steroids, DMARD's, or biologic drugs **and break out with chicken pox or shingles.**
- If you are on anti-inflammatory medicine such as Naprosyn, Ibuprofen, Celebrex, Mobic, Relafen, etc., and develop **persistent stomach aches**, vomit blood, have black tarry stools, or have blood in or mixed with your bowel movements.
- If you develop an increase in joint swelling and pain or are unable to use a joint.
- If you develop **high fever** combined with an increase in swelling and pain in any joint.
- If you develop persistent fever.
- If your condition gets worse and you are having difficulty getting around.
- If you develop a rash or hives.
- If you develop **chest pain**, especially if it occurs with shortness of breath, fainting, or turning blue around the mouth or in the hands.
- If you develop hoarseness.
- If you feel depressed or begin doing poorly at school, or quit playing or interacting with friends, then call the nurse to discuss this.
- If you have major behavior changes.

Notes

[illegible]

Chapter 8

Tools and Record Keeping



© PR-COIN (Pediatric Rheumatology Care and Outcomes Improvement Network)



This Chapter includes examples of tools you can use for record keeping or keeping track of things. Research has shown that keeping records and making plans are helpful ways for patients to “stay on track” with their arthritis and goals. It is often helpful to write down information. If you think of a question or want to ask your provider, nurse or therapists, **write it down!** Then, bring your questions to the clinic.

When you come to clinic appointments or to the hospital someone on your health care team may ask you questions about how you are managing things, any concerns, worries, or things that make it hard for you to take care of yourself. We have included those forms so you will be familiar with them. Please let them know if you are having any problems following the care plan.

You can choose which tools may be helpful for you. Please feel free to make extra copies of the tools for yourself for future use.



**Take control of
your
medical records**

Office Visit

This sheet can be used or copied to keep track of each visit, discussions with your provider, and your disease. It can also be used to update your primary care provider about your arthritis.

Date: _____

- Changes since your last visit? (ex. symptoms, concerns, medicine changes, other illnesses)

- Questions for your health care provider?

- Tests results discussed

- Changes made at today's visit (including treatment changes and tests/labs to be done)

- Need any refills?



Self-Management Assessment

This assessment may be given to you at your visit or before. It is important that you answer carefully and honestly.

1) I would like to discuss the following things with my health care team today:

- a) _____
- b) _____
- c) _____

2) I am certain that I can do all the things necessary to manage my condition/my child's condition on a regular basis.

0	1	2	3	4	5	6	7	8	9	10
Not										Very
Certain										Certain
At All										

3) I worry about my medical needs or my child's medical needs.

None of the time	A little of the time	Some of the time	Most of the time	All of the time
---------------------	-------------------------	---------------------	---------------------	--------------------

4) I make plans or set goals for my visits / my child's visits and make sure our health care team knows what I want to accomplish at each visit.

None of the time	A little of the time	Some of the time	Most of the time	All of the time
---------------------	-------------------------	---------------------	---------------------	--------------------

5) Over the past week, I was able to stick with my care plan/ my child's care plan.

None of the time	A little of the time	Some of the time	Most of the time	All of the time
---------------------	-------------------------	---------------------	---------------------	--------------------

6) Over the past week, I missed a medication dose about _____ times.





7) What things, if any, are going on in your life that could make caring for your condition / your child's condition especially hard?

Barriers Checklist Parent/Caregiver

Parents often tell us that it is hard to follow the treatments. Please let us know what may get in the way for you. Parents may get this check list to fill out at your visit.

Things that Get in the Way of Taking Your Medicine or Doing Treatments (Caregiver version)

We know the treatments that your child has to do can be hard to follow. Some caregivers say the following things get in the way of doing treatments.

	<i>Please circle the treatments that are currently prescribed to your child.</i>			
	Oral medications 	Injections 	Infusions 	Physical and Occupational Therapy 
<i>Please check the boxes that apply for each of your child's circled treatments:</i>				
My child hates the taste of the medicine	<input type="checkbox"/>	N/A	N/A	N/A
The pills are hard to swallow	<input type="checkbox"/>	N/A	N/A	N/A
We forget to do the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We run out of the medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A
MY CHILD:				
• Does not like the side effects of the treatment (e.g. nausea)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Refuses to do the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Feels he/she does not need the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Does not want others to know that he/she takes/does the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
THE TREATMENT:				
• Is painful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Does not work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Is inconvenient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Gets in the way of our other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Makes me uncomfortable or upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Has instructions that are hard to understand or follow through with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Costs too much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Makes me worry about future side effects/consequences	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• May impact my child's ability to have children in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NONE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any concerns about treatments that your child had in the past? ☐ YES ☐ NO





Reviewed by (provider): _____ Notes: _____

Barriers Checklist Patient

Patients often tell us that it is hard to follow the treatments. Please let us know what may get in the way for you. You may get this checklist to fill out at your visit.

Things that Get in the Way of Taking Your Medicine or Doing Treatments (Patient version)

We know the treatments that your child has to do can be hard to follow. Some caregivers say the following things get in the way of doing treatments.

	Please circle the treatments that are currently prescribed for you.			
	Oral medications 	Injections 	Infusions 	Physical and Occupational Therapy 
<i>Please check the boxes that apply for each of your circled treatments:</i>				
I hate the taste of the medicine	<input type="checkbox"/>	N/A	N/A	N/A
The pills are hard to swallow	<input type="checkbox"/>	N/A	N/A	N/A
I forget to do the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We run out of the medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A
I do not like the side effects of the treatment (e.g. nausea)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I refuse to do the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel I do not need the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I do not want others to know that I take/do the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
THE TREATMENT:				
• Is painful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Does not work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Is inconvenient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Gets in the way of our other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Makes me uncomfortable or upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Has instructions that are hard to understand or follow through with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Costs too much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Makes me worry about future side effects/consequences	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Worry about my ability to have children in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NONE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Reviewed by (provider): _____ Notes: _____

(name)

-
-
-

-

-
-
-
-

- | | | | | | | | | | | |
|-------------|---|---|---------|---|---|---|---|---|---|------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Not Certain | | | | | | | | | | Very |
| At All | | | Certain | | | | | | | |

6. In what way can that person help me follow my plan and reach my goal?

- ☐ email
- ☐ phone
- ☐ text message
- ☐ returning to clinic or other contact

Signature: _____ Date _____
Reviewed By: _____ Date _____

Telephone Log

[illegible]

Record of X-Rays/MRIs

Date: ____/____/____ Taken at: _____ Doctor: _____

Type of x-ray: _____

Record of X-Rays/MRIs

Date: ____/____/____ Taken at: _____ Doctor: _____

Type of x-ray: _____

Record of X-Rays/MRIs

Date: ____/____/____ Taken at: _____ Doctor: _____

Type of x-ray: _____

Record of X-Rays/MRIs

Date: ____/____/____ Taken at: _____ Doctor: _____

Type of x-ray: _____



Record of Prescription Medications

Date: ____/____/____ Drug: _____/Doctor: _____

Pharmacy: _____ Pharmacy phone number: (____) _____

Duration (start & stop dates)	Dosage	Refill Dates	Comments

Record of Prescription Medications

Date: ____/____/____ Drug: _____/Doctor: _____

Pharmacy: _____ Pharmacy phone number: (____) _____

Duration (start & stop dates)	Dosage	Refill Dates	Comments

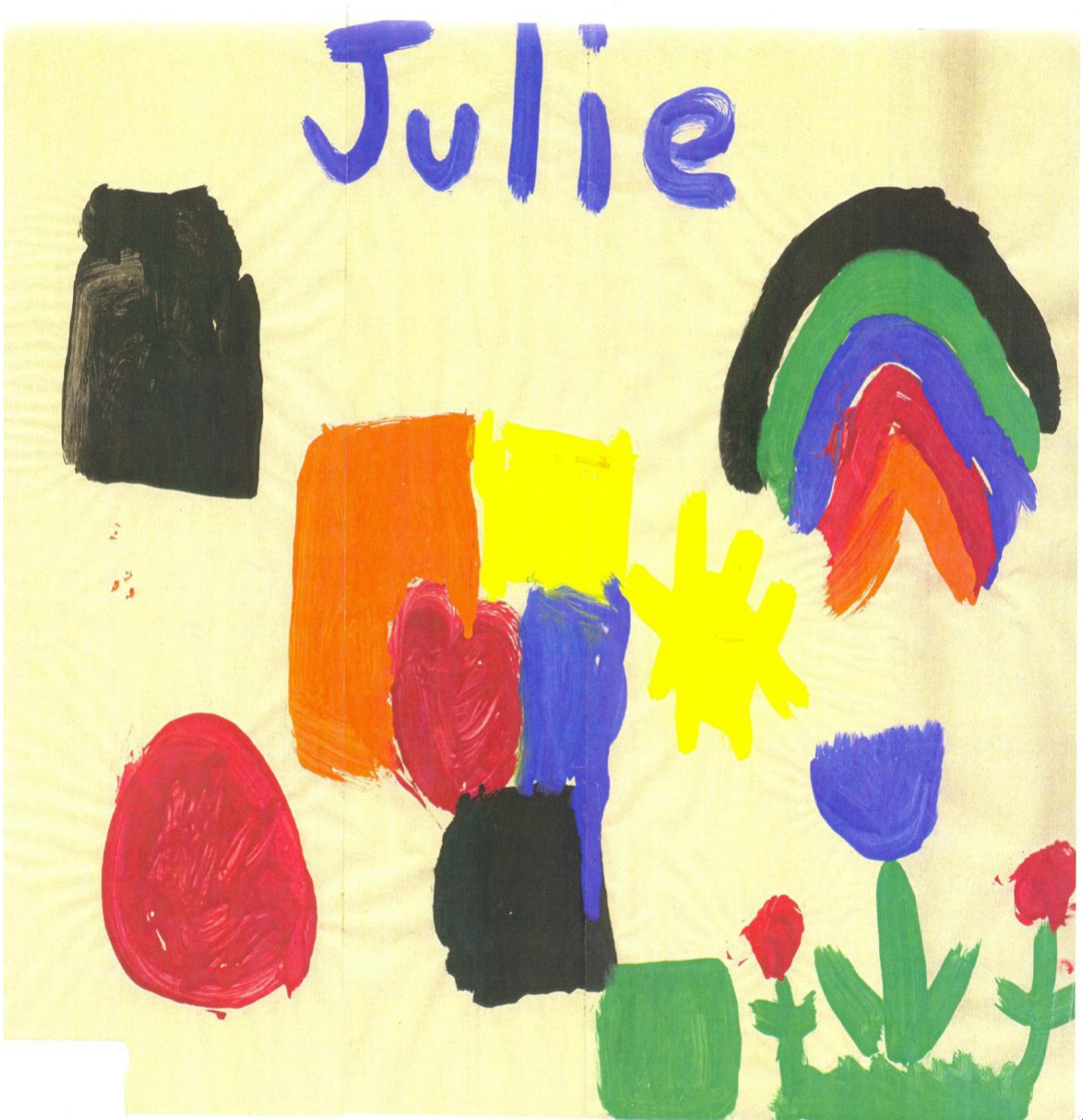


Notes

[illegible]

Chapter 9

Website Resources



The Arthritis Foundation

www.arthritis.org

The Arthritis Foundation is a leader in providing information and resources for patients and families. They have help and support programs, support research, and advocate at the state and federal level for the needs of patients with arthritis.

The Arthritis Society

<https://arthritis.ca/>

The Arthritis Society is Canada's primary health charity for providing education, programs and support to the over 4.6 million Canadians living with arthritis.

CARRA (Childhood Arthritis and Rheumatology Research Alliance)

<https://carragroup.org/>

The mission of CARRA is to conduct collaborative research to prevent, treat and cure pediatric rheumatic diseases. CARRA conducts research studies on JIA, lupus, juvenile fibromyalgia, and many other rheumatic diseases. CARRA members include rheumatologists, fellows, nurses, psychologists, research associates, patients, and leaders of different organizations.

About Kids Health

<http://www.aboutkidshealth.ca/>

This is a website with trusted information about a variety of complex child health conditions from the Hospital for Sick Children. Look under "A" for arthritis and also under the Resource Centres – "JIA Resource Centre" for information about arthritis for parents and kids. The JIA Resource Centre is also home to "Teens Taking Charge", an online education tool especially for kids with JIA.

Kids Get Arthritis Too

<http://www.kidsgetarthritis.org/>

This is a special section of the Arthritis Foundation's website. It is the online home for the 300,000 families living with juvenile arthritis.



Kids Health

<http://kidshealth.org/en/kids/center/htbw-main-page.html>

Kids Health is a website with all sorts of information about kids or teen health. It has information on different diseases or conditions, nutrition, emotions, school, first aid and safety, and more. There are special sections for parents, kids, and teens.

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

www.niams.nih.gov

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases. They support the training of basic and clinical scientists to carry out this research. NIAMS works to share the information and research progress in these diseases.

www.niams.nih.gov/health_info

This is a health information page on the website. It has information about many different types of arthritis including JIA.

www.niams.nih.gov/health_info/Kids/default.asp

This section helps you learn habits to you keep your bones, joints, muscles, and skin healthy for years to come.

PR-COIN

<http://pr-coin.org>

PR-COIN is a Learning Health System. The goal of PR-COIN is to develop and evaluate specific disease management strategies to improve the care of children with JIA. Quality Improvement research is done to determine the best ways of providing care and how best to get the strategies of care into practice for kids with JIA.

PR-COIN is a network of Patients, Families, Rheumatologists, Nurses, Therapists, Social Workers and support staff at rheumatology centers who work together to change and improve how care is delivered to children with JIA.



Chapter 10

Appendix (Word List)



Word List

Acute – happens suddenly or over a short period of time.

Alopecia (al-uh-**pee**-shee-uh)—hair loss.

Anemia (uh-**nee**-mee-uh) – low red blood cell count. This causes a low oxygen-carrying ability in the blood.

Antibody (an-ti-bod-ee) – a protein substance made by white blood cells that help in response to specific antigens. (see antigen below).

Antigen (an-ti-jen) – a foreign material to the body. It causes the body to make an antibody as a defense, such as to infections with a virus or bacteria. There are also “self-antigens.” These may be involved with certain conditions like arthritis.

Anti-inflammatory – (an-tee-in-**flam**-uh-tor-ee) works against swelling and irritation.

AntiNuclear (an-tee-**noo**-klee-er) **Antibody (ANA)** – a protein which is often positive in some types of JIA. This is a blood test that can be helpful in predicting which kids are with JIA are likely to have eye disease.

Arthralgia (ahr-**thral**-juh) – joint pain.

Arthritis (ahr-**thrahy**-tis) –swelling in the joints.

Biologics (bahy-uh-**loj**-iks) – a type of medicine used to treat arthritis.

Blood cells –

- a. Red blood cells – carry oxygen from the lungs other areas of the body.
- b. Platelets – help to make the blood clot.
- c. White blood cells – used to help fight infection; there are several types of white blood cells.

Cartilage (**kahr**-ti-lij) – the tissue in the joint that covers the bone and provides a “cushion” to the joint.

CBC – Complete Blood Count. This is a common blood test that checks all cell types in the blood like red blood cells, white blood cells, and platelets. This blood test is often used to check for anemia, bleeding problems, or infection.

Chronic – (**kron**-ik) lasting for a long period or an indefinite period of time.



Complements –(**kom-pluh-ments**) a group of proteins that are part of the immune system (see immune system below). Complements help in killing bacteria, viruses, or infected cells.

Contracture (**kuh n-trak-cher**)– a temporary or permanent loss of some range of motion in a joint.

CRP—a protein that the liver releases into the blood at the start of an infection or inflammation. The CRP can be high if a person is having an arthritis flare-up.

Diagnosis – (**dahy-uh g-noh-sis**) the name of a disease based on its signs and symptoms and test results.

Dietitian – (**dahy-i-tish-uhn**) a person who check your growth, teaches nutrition and meal planning, and prescribes special diets as needed.

Edema (**ih-dee-muh**) – swelling caused by fluid in tissues.

Erythrocyte Sedimentation Rate (**ih-rith-ruh-site**) (**sed-uh-muhn-tey-shuhn**) rate — This test is often called the "sed rate." The sed rate reflects inflammation in the system or tissue injury and varies from patient to patient. The ESR can be high if a person is having an arthritis flare-up.

Fatigue – (**fuh-teeg**) being very tired.

Fellow – (**fel-oh**) a doctor who is getting special training in a certain area, like rheumatology.

Flare – (**fl-air**) an increase in the symptoms or signs of a disease such as arthritis.

Flexion contracture (**flek-shuhn**) – a temporary or permanent inability to fully straighten a joint.

HLA typing—certain genes which can be found on the surface of white blood cells. By doing HLA typing, certain genes can be identified with different types of diseases.

Immune system – the body's system of defense against disease.

Immunoglobulins (**im-yuh-noh-glob-yuh-lins**) – proteins in the body that are increased as a result of inflammation.

Immunosuppressive (**im-yuh-noh-suh-pres-iv**) – something (usually medicines) that causes a decrease in the body's defense against disease

Inflammation (in-fluh-mey-shuh n) – swelling and irritation. A reaction of the body, which can result in symptoms such as redness, swelling, heat, or pain.

Iridocyclitis (ir'ī-dō-sī-klī'tīs) – inflammation of the iris and ciliary body of the eye. Also called uveitis and iritis.

Iritis (ahy-rah-y-tis) – inflammation of the iris or colored part of the eye.

Joint – a place where two bones come together.

Joint effusion (ih-fyoo-zuh n) – the swelling, or fluid, in a joint.

Juvenile idiopathic arthritis (JIA) –(joo-vuh-nl) (id-ee-uh-path-ik) a chronic arthritis of children that begins before the age of 16.

Ligament (lig-uh-muh nt) – a thick, rubber band-like tissue which connects bones together.

Morning stiffness – the period of time after a child wakes up when he or she feels stiff and has difficulty moving.

NPO – nothing to eat or drink by mouth.

NSAID (non-steroidal anti-inflammatory drug) – a drug containing no steroids that helps control swelling; usually the first type of drugs used in treatment of JIA.

Osteoporosis (os-tee-oh-puh-roh-sis) – the decreased mineral content or thinning of the bones.

Pericardium (per-i-kahr-dee-uh m)– the outer lining of the heart.

Prognosis (prog-noh-sis)– a prediction of the course of a disease or outcome of a disease.

Range of motion – the maximum amount of movement that a joint can move.

Remission (ri-mish-uh n)– having no signs or symptoms of a disease.

Rheumatoid factor (roo-muh-toid) — a protein which is made by the white blood cells. A blood test to check for this is done when you are diagnosed. It is rarely positive in children.

SGOT/SGPT – two blood tests which check the liver. These may also be known as AST/ALT.



Slit-lamp exam – an eye exam that is done to see if the back of the eye is inflamed.

Subcutaneous (suhb-kyoo-**tey**-nee-uh s) – under the skin, in the fatty layer. Most biologic injections are given in these parts of the body.

Synovial fluid (si-**noh**-vee-uhl) – the fluid that is within the joint and lubricates and nourishes the joint.

Synovial lining – the tissue which lines or surrounds the inside of the joint. It makes synovial fluid.

Tendon (**ten**-duh n) – a thick, rubber band-like tissue at the end of a muscle which attaches the muscle to the bones, thus allowing a joint to move. Tendons are partially covered by synovium like a sleeve.

Tenosynovitis (ten-oh-sin-uh-**vahy**-tis) – inflammation or swelling of the synovial sheaths (or sleeves) that line the outside of tendons.

Urinalysis (yoo r-uh-**nal**-uh-sis) – tests done on urine to check the function of the kidneys.

Uveitis (yoo-vee-**ahy**-tis)—inflammation of the uvea which has 3 layers under the white of the eye. The 3 parts are:

- (1) the iris, which is the colored part of the eye;
- (2) the choroid layer, which is the layer of blood vessels and tissue between the white of the eye and the retina; and
- (3) the ciliary body, which is the structure in the eye that secretes liquid in the eye