

EDUCATING CHILDREN & FAMILIES ABOUT JUVENILE IDIOPATHIC ARTHRITIS (JIA)

A CLINICIAN'S GUIDE

INTRODUCTION

The following manual is designed as a flexible guide to providing disease education to patients with newly diagnosed Juvenile Idiopathic Arthritis (JIA), and their families. The education program has been developed based on the recommendations from patients, parents and the Victorian Paediatric Rheumatology 'Best Practice Consortium'. It is based on the principle that all children and families diagnosed with JIA should be offered comprehensive multidisciplinary assessment and be supported through an individualized education program. Although based on a model of care in which a Rheumatology Nurse plays a principal role in the education program, the manual can also be used by other medical, nursing and allied health clinicians.

The literature on patient and family education in the context of chronic disease indicates that the positive outcomes of patient education are:

- Reduced misinformation and anxiety about condition and treatment
- Improved self-care and management by parents
- Improved treatment compliance
- Early intervention for psychosocial difficulties, resulting in improved psychosocial outcomes and reduced referral to tertiary mental health services.
- Early detection of complications
- Improved communication with patient and family, and community health care workers
- Reduced ad hoc contacts with health providers, resulting in more effective use of clinician time and resources
- Compliance with ethical and consumer participation standards

In addition to providing an approach to the education of patients with JIA and their families, this manual aims to provide guidance regarding:

- Building partnerships with patients and their families
- Engaging patients and families in decision making about the management of JIA, including the formulation of JIA management plans, and problem-solving difficulties in compliance with prescribed medication and physical therapy treatments.
- Teaching patients and parents medication administration techniques and management strategies for procedural and chronic pain associated with JIA.

HOW TO USE THIS MANUAL

The following resources are included in this manual:

1. JIA education and assessment program flow chart
2. Rheumatology Nurse Assessment (**Attachment One**)
3. JIA clinician session plans
4. JIA patient and family power point presentation: Module 1 & 2 (**Attachment Two**)
5. Patient & family JIA information sheets & worksheets (**Attachment Three**)
6. Rheumatology Treatment record (**Attachment Four**)

1. JIA EDUCATION & ASSESSMENT PROGRAM FLOW CHART

The flow chart outlines process and timing guidelines for the provision of patient and family education and referral considerations. It provides three different delivery options for education to maximize the opportunity for individualisation of the education program.

Important points to remember when arranging an education and assessment program for an individual patient:

- Ensure that the patient and family have received the suggested reading material about JIA (“JIA information pack”).at diagnosis prior to the commencement of the formal education process.
- Aim to conduct the first session within 7-14 days of diagnosis.
- Choose the right education and assessment program option for each patient and their family.
- Consider patient’s school commitments and parents’ working commitments when scheduling the education sessions.

Flexibility: The modules can be used in any order to ensure the education and assessment program meets the individual educational needs of the patient and family. Give the patient and family time to practice the skills they develop in the sessions, and provide ongoing feedback and support until competencies are achieved or information is understood.

2. RHEUMATOLOGY NURSE ASSESSMENT

The delivery of detailed and individualized education by the rheumatology nurse to the patient and family relies on the nurse having a comprehensive understanding of the patient and his/her family’s physical, psychosocial, developmental and educational needs and willingness to learn.

The nursing assessment explores all of these aspects in detail prior to commencing the child and his/her family’s education program.

3. JIA EDUCATION SESSION PLANS

These documents guide educators about the purpose and objectives of each education module, methods of presenting information, content suggestions and patient and parent resources to support the content taught in each session. At the end of each session plan there is also a guide for the rheumatology nurse to assessing patient and family learning. The questions provided will assist you

4. JIA PATIENT AND FAMILY POWER POINT PRESENTATION: MODULE 1 & 2

A PowerPoint presentation has been developed to deliver detailed and visually stimulating education. The presentation also provides the rheumatology nurse with guide to what essential information should be covered during modules one and two. It is important to remember that the materials used to deliver education should be appropriate for the audience. The PowerPoint presentation may be appropriate for parents however play and drawing may be used for children and informal less structured sessions may be used for adolescents.

5. PATIENT AND FAMILY INFORMATION HANDOUTS & WORKSHEETS

The patient and parent information sheets referred to throughout the session plans have been developed to support the content delivered in each education module. The worksheets have been included to aid the nurse, psychologist or clinician in stimulating the patient and his/her family to be actively involved in the session, and develop skills and self management plans specific to their needs. It is recommended that patients and parents receive the relevant information handouts to read prior to attending each education session.

6. RHEUMATOLOGY TREATMENT RECORD

The patient's treatment record is for use by every member of the child's treating team including the patient and their parents. It has been designed to record:

- The patient's treating team and contacts
- What to do in a flare up
- Medications
- Appointments
- Tests and procedures
- Things to ask or tell the treatment team at the next appointment

PREPARING FOR AN EDUCATION & ASSESSMENT PROGRAM

Preparation is essential. Things to consider when preparing:

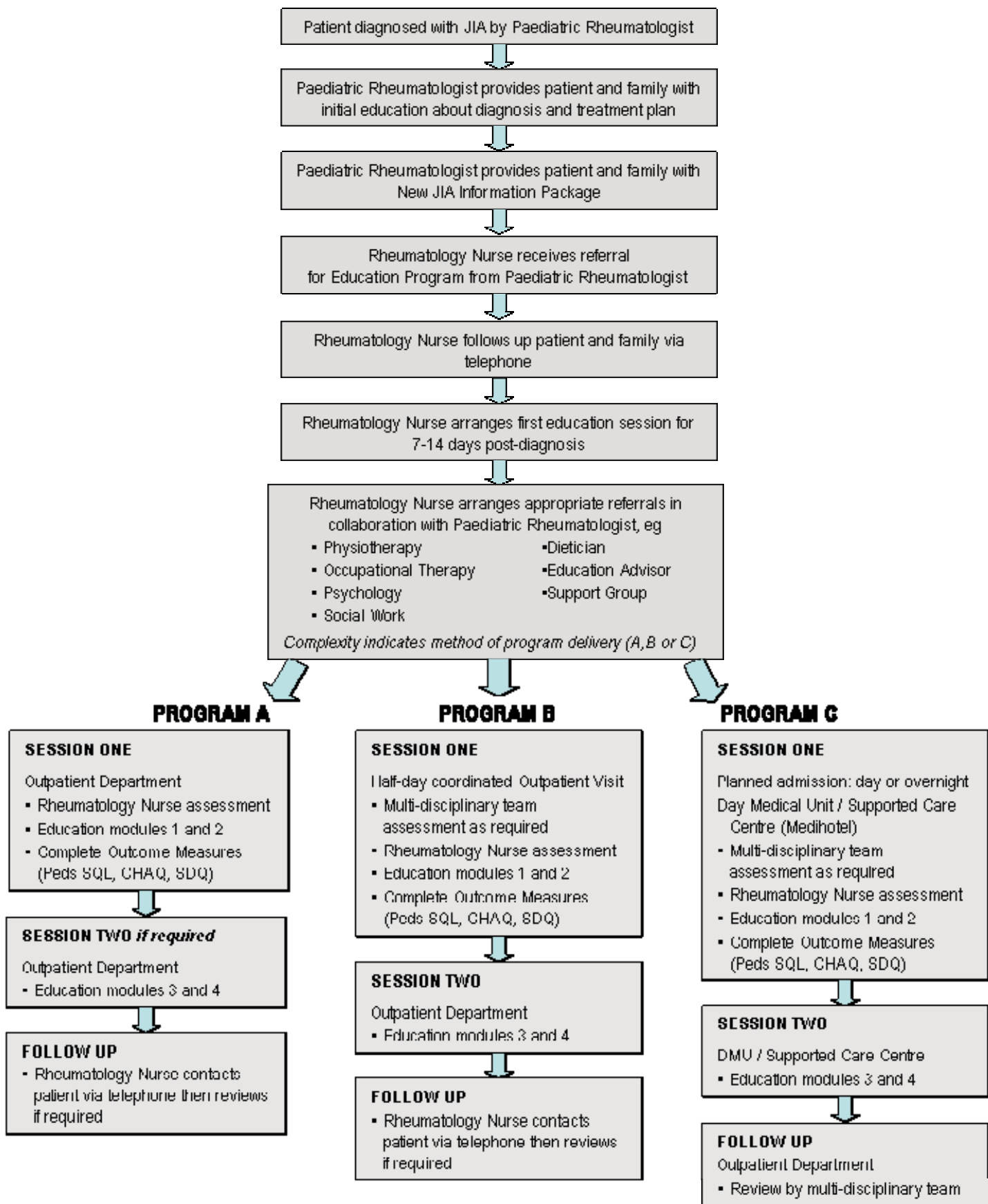
- Best times to schedule appointments and/or admissions.
- Coordination with other health professionals required to review, assess and/or teach patients and families.
- The need to be flexible
- Discuss patient's presentation, history, treatment plan and referral considerations with the patient's treating rheumatologist.
- Ensure all the materials required for each session are at hand and that sufficient copies to give to the family are available.
- Make certain the education and assessment program that is arranged is based on the needs of the individual patient and their family.

Growing up with JIA can be both challenging and frustrating. With education, support and coordinated care from a multi-disciplinary team, children with JIA and their families can learn to live full and active lives and be given a sense of control of their disease and an understanding of their central role as part of the 'treatment team'.

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Section One: JIA education program flow chart

Both consumers and the literature indicate that minimal education should be delivered at the initial diagnostic visit. It is recommended that the patient and family assessment and education program commence with a 1-2 day admission or outpatient visit for initial assessment by all members of the multidisciplinary team (please refer to flowchart on page 6). The rheumatology nurse should be introduced at the diagnostic visit if possible. Alternately, the rheumatology nurse should contact the family by telephone within 4-7 days to schedule an appointment to commence the program. The education program should begin within 7-14 days after diagnosis.



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Section Two: JIA Education Session Plans

Module One: What is Juvenile Idiopathic Arthritis (JIA)?

Module one introduces the patient and family to their education program. It is important to plan the program with patients and their families, encouraging them to actively participate in tailoring a program specific to their needs, problems and concerns. It is recommended that modules one and two are incorporated into one session

Reminder: It is important the patient and family receive the suggested reading materials about JIA (“JIA information pack”) at diagnosis, prior to the commencement of the formal education process.

AIMS OF EDUCATION MODULE ONE

- To provide patient and family with an understanding of what Juvenile Idiopathic Arthritis JIA is.
- To provide an overview of who is in the rheumatology treatment team.

1. Supporting Material Required

- JIA information pack (available in child, adolescent and parent version)
- JIA patient and family power point presentation

2. What is Juvenile Idiopathic Arthritis (JIA)?

Using the above materials review the following information with the patient and family, remembering to pitch your discussion at the appropriate developmental level.

- Define the terms Juvenile, Idiopathic and Arthritis.
- Discuss other terms used to describe JIA, for example; JCA, JRA.
- Explain what causes JIA, including:
 - How the immune system works and;
 - How the immune system is altered in auto-immune conditions
- Explain what happens to the joints in JIA. Support this information with a diagram of a normal and an active joint.
- Explain what ‘chronic’ means
- Discuss how common JIA is
- Discuss how clinicians diagnose JIA, including:
 - Clinical examination and its importance;
 - The significance of specific blood tests and;
 - The use of medical imaging.

- Explain the different types of JIA and how they are classified. If the patient's JIA has been classified you may provide specific detail about the patient's sub-type, if not, this information may be discussed when the sub-type has been confirmed.
- Discuss the patient's and family's concerns about what the future holds, and provide information about available supports.
- Discuss who makes up the treatment team outlining:
 1. each health professionals' role and how they can help the patient and family and;
 2. how to access each member.

3. IDENTIFICATION OF PATIENT AND PARENT FEARS ABOUT JIA

It is very important that you address any fears, misconceptions and concerns patients and their families have about JIA at diagnosis. In order to stimulate discussion around thoughts, feelings and coping strategies you may wish to consider using some of the following simple questions:

- What do you know about arthritis? Important to differentiate JIA from other forms of arthritis e.g. in adults.
- What do you want to know?
- How will you tell your friends/family/school etc?
- What are you worried about?
- What help do you think you might need?
- What can you do to help yourself/your child feel better?

4. ACCESS TO INFORMATION

It is important to guide patients and parents to reliable sources of information about JIA. Encourage patients and families to share with you information they have heard or read, and any questions or concerns it raises, especially as the information may not be accurate or relevant to them.

5. ASSESSMENT OF PATIENT/FAMILY KNOWLEDGE

Finish the session by going through the assessment of patient/family knowledge tool for module one. Use the questions provided to assess the patient and/or parent level of understanding. Allow time for further questions, discussion and clarification.

Module One: Assessment Guide

A guide to assessing patient/family knowledge post module

ASSESSMENT OF KNOWLEDGE (Questions used to encourage patients & parents to demonstrate their knowledge of JIA) Question A = Parent Question B = Child/Young person	PERFORMANCE INDICATORS	ASSESSMENT SCALE		
		0= Does not understand	1= Needs review	2=Understands well
1a. "Tell me how you would explain your child's JIA to a friend or relative?"	Check for in answer: 1) Name of sub-type 2) Knowledge of disease course 3) Prevalence 4) Etiology 5) How it is diagnosed	0	1	2
1b. "Tell me what you would tell your friends about your JIA?"				
2a. "What are the signs and symptoms of active JIA?"	Check for in answer: 1) Heat 2) Weakness 3) Swelling 4) Pain 5) Restricted movement 6) Rash (SoJIA) 7) Temperature (SoJIA)			
2b. "Can you draw for me a picture of your arthritis?"				
3a. "What would you do at home if your child said he/she was sore?"	Check against individual flare-up plan drafted during this module, including pain management strategies.			
3b. "Write down or draw the things you might do if you were feeling sore at: ➤ HOME ➤ SCHOOL				
4a. "When would you contact your child's doctor or rheumatology nurse about your child's JIA?"	Check for in answer: 1) Signs & symptoms of a flare-up 2) Signs & symptoms of complications of JIA			
4b. "Tell me how you would know if you or your parents need to contact your doctor or rheumatology nurse about your JIA?"				

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Module Two: Treatments

As outlined in module one it is recommended that modules one and two be incorporated into a single session where possible, however they can be delivered separately especially when periodic up-dates are required or treatments change. This education module is about the treatment of JIA. The session is designed to provide patients and their parents with an overview of the main ways of treating JIA, followed by a discussion about the specific treatments and or medications recommended for this patient. This module is highly recommended when any child commences DMARDS or Biologics. Education about specific medications, their safety, use and skill development in administration are essential to developing an effective treatment plan that the patient and family will be able to adhere to.

AIMS OF EDUCATION MODULE TWO

- To provide patient and family with an understanding of what treatments & medications are used to manage JIA.
- To provide adequate support and opportunity for patient and family skill development

1. SUPPORTING INFORMATION REQUIRED

- Information Sheet - JIA: Medication Overview
- Information Sheet - JIA: Treatment Overview
- Information Sheet– Physiotherapy and JIA
- Information Sheet– Methotrexate
- Information Booklet - Subcutaneous Methotrexate
- Information Booklet– Anakinra
- Rheumatology Treatment Record

2. TREATING JIA

Using the relevant JIA information sheets, JIA power point presentation and treatment record as a guide, review the following information with the patient and family, remembering to pitch your discussion at the appropriate developmental level.

- Discuss the goals of treatment. For example:
 1. to reduce inflammation
 2. to reduce pain (usually due to inflammation)
 3. to slow down or prevent the damage to joints
 4. to make sure joints keep working as best they can

- Provide an overview of the treatments available and when they may be recommended. For example:
 1. medications to control the inflammation
 2. exercises to keeping the joints moving well
 3. splints to support the joints
 4. joint injections to reduce inflammation in particular joints
 5. pain management strategies to reduce pain and to help your child cope with pain
- Review and discuss the rationale for the use of each specific treatment recommended for your patient. These treatments should be recorded in the patient's treatment record. Be prepared to answer questions about safety, side effects and alternatives to the recommended treatment.
 - Formulate a flare-up plan with your patient and their family. Make sure they have a clear understanding of who to call and in what circumstances.

3. MEDICATIONS FOR JIA

Discuss the following information about each individual medication prescribed for your patient:

- The name of each medication including the generic and the trade name.
- The purpose of the medication.
- How the medication works.
- The dose and frequency of administration.
- How long will the medication need to be taken for.
- Drug monitoring.
- Side effects and measures that can be taken to reduce or eliminate side effects of medications.
- Special instructions for taking the medication.
- When to seek help.
- Additional things to be aware of, such as interaction effects etc. For example: Immunisations, alcohol use, Varicella.

4. SKILL DEVELOPMENT

The use of subcutaneous methotrexate and biologics is becoming more common. It is therefore very important that adequate support and opportunity for skill development be given to patient and families to decrease their reliance on health professionals for the administration of these medications.

Using the tools available for the administration of subcutaneous Cytotoxics and Biologics you will be able to empower patients and their families to administer these medications in the home.

Some tips for teaching subcutaneous administration:

- Provide patients and families with the reasons for subcutaneous administration.
- Address any procedural pain concerns patients may have prior to teaching. It is essential these fears, concerns and problems are addressed before proceeding.
- Provide a detailed step-by-step “how to” guide that patients can take home with them.
- Demonstrate to the patient/family how to administer the injection.
- Provide sufficient time to practice using the equipment before the first injection.
- Supervise patient/family administering 1-3 injections, or until both you and the family are confident they can administer safely in the home.

5. IDENTIFICATION OF PATIENT AND PARENT FEARS ABOUT TREATMENTS FOR JIA

It is very important that you address any fears, misconceptions and concerns patients and their families have about any of the medications and or treatments they have been recommended. In order to stimulate discussion around thoughts and feeling you may consider using some of the following simple questions:

- What do you think about the treatment you have been recommended to use?
- What worries do you have about you/your child taking this medication?
- Do you think you will have any problems following the treatment? E.g. do you hate taking pills or having injections? Make a plan to manage potential problems.
- What have you heard about treatments for arthritis – explore ideas about CAMs, side effects etc.
- What bothers you about giving your own/your child’s medication? Elicit concerns about taking responsibility, fears about hurting or harming the child, issues about the parent-child relationship that may interfere with treatment.
- How will you manage/help your child manage having needles at home? Discuss coping strategies for procedural pain.
- If required, arrange a time for module three: coping with procedures.

6. TREATMENT RECORD

It is recommended that you review the patient’s treatment record with the patient and their family to reinforce the child’s medication and or treatment schedule and ensure the medication plan is recorded correctly and clearly in the patient’s treatment record.

7. ASSESSMENT OF PATIENT/FAMILY KNOWLEDGE

Finish the session by going through the assessment of patient/family knowledge tool for module two. Use the questions provided to assess the patient and/or parent level of understanding. Allow time for further questions, discussion and clarification.

Module Two: Assessment Guide

A guide to assessing patient/family knowledge post module

ASSESSMENT OF KNOWLEDGE (Questions used to encourage patients & parents to demonstrate their knowledge of JIA). Question A = Parent Question B = Child/Young person	PERFORMANCE INDICATORS	ASSESSMENT SCALE 0= Does not understand 1= Needs review 2=Understands well		
		0	1	2
5a. "Tell me the types of different things used to treat JIA, & how they can help your child"	Check for in answer: 1) Medications 2) Physical Therapies 3) Psychosocial 4) Rationale for use of each			
5b. "Tell me what things you can use to treat your JIA to make you feel better?"				
6a. "Tell me about the medications your child has been prescribed"	Check for each (prompt if necessary): 1) What does it do 2) How & when do you take it? 3) What side effects & interactions do you need to know about? 4) How do you store it at home/school? 5) What monitoring do you need? 6) What do you do if you run out of it?			
6b. "Tell me about the different medicines your rheumatologist has asked you to take for your JIA"				
7a. "Tell me about your child's treatment plan"	Check against personal treatment plan in detail.			
7b. "Tell me about your treatment plan"				
8a. "When would you contact your child's doctor or rheumatology nurse about your child's medications?"	Check for in answer: 1) Signs & symptoms of side effects of each medication. 2) Administration errors. 3) JIA symptoms increasing and not subsiding			
8b. "Tell me how you would know if you or your parents need to contact your doctor or rheumatology nurse about your medications?"				

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Module Three: Procedural Pain Management

The following education module has been designed to prepare patients and their families for procedures. Common procedures used for the management and treatments of JIA include:

- Joint injections
- Blood tests
- Sub-cutaneous injections

These procedures can be painful, and anxiety and tension often make pain worse. This module will assist you to help children and parents learn to manage their/their child's pain and anxiety during procedures.

Aims of Education Module Three

- To provide the patient and family with a detailed understanding of the procedures they will have.
- To provide an understanding of the strategies that are available to manage pain and anxiety during procedures, and for patients and parents to develop skills in using these.
- To provide patients and family with the opportunity to develop their own personal coping/comfort plan for procedures.

1. SUPPORTING INFORMATION REQUIRED

- Information Sheet – Helping your child manage pain during procedures.
- Information Sheet – Relaxation instructions to use with your child.
- Information Sheet – Joint Injections

2. PREPARING A CHILD FOR A PROCEDURE

Give explanations the child will understand.

- Speak with the child's and their parent/s and explain the procedure in detail. Provide a rationale for why the procedure is necessary.
- Provide the child with a clear, simple and accurate explanation of the procedure. Describe what they will feel, hear, see and smell in a way that the child will understand.
- Younger children are often helped by playing with some of the equipment that may be used for the procedure, whilst adolescents may like diagrams.
- Explain the information in small pieces, slowly, and repeat the necessary information as often as required.

- Be honest; do not lie to children about pain. Children who are told a painful treatment or procedure won't hurt are likely to get a shock when it does. This is likely to increase their anxiety. They may refuse other procedures later on. It is better to prepare the child honestly and to talk about strategies they can use to cope with a procedure.
- Some children like to know exactly what is going to happen during a procedure. Others want only a few details. Some children like to know things long before they happen, while others like to find out closer to the time. Always ask the parent, child or adolescent what they would prefer.

Expression of feelings

It is very important that you address any fears, misconceptions and concerns patients and their families have about the specific procedure. Assist the child to ask questions and express how they are feeling. For example:

- Is there anything about the procedure you are afraid of?
- Is there anything about the procedure that worries you?
- What helps you to feel better about a procedure? Help the child identify specific strategies that they will use and practice them beforehand.

For younger children you may use dolls, puppets, drawings or drawings to assist them to express their feelings.

3. DURING THE PROCEDURE

Parent Information Sheet - 'Helping your child manage pain during procedures' outlines some very effective strategies parents and clinicians can use to manage pain and anxiety associated with procedures. Some of the key strategies include:

- Encourage the child's parent to be present during the procedure where possible.
- Remind the child/parent of the coping strategies they had decided on in the preparation session.
- Show confidence in the coping strategies and encourage the child's parent to be also. Children say parents are their greatest source of strength when dealing with pain. But they can also react to parents' anxiety about pain.
- Give some control to the child. For example, the child might decide whether to sit in a chair or on their parent's lap for an injection, and will probably feel less pain than a child who has no choice. Even very young children can be allowed to decide some parts of their treatment, for example, which arm to have blood taken from, or whether to have a Band-aid.
- Talk the child through the pain. The reality of a painful experience should be acknowledged and accepted, while at the same time talking to the child in a way that helps the child manage this. For example, you could say: "I know this medicine stings when it goes in." Follow this with some help, for example: "...but if you take a breath and blow out slowly, it may hurt less." Children can often use suggestions for pain relief such as, "Let the pain just drain away down and

out of your body into the bed and away... good... that's it, let it go." Use the child's own language and the child's favorite activities or experiences.

- Distraction is especially helpful for short pain, like pain from injections. All ages of children can be distracted with:
 - Music,
 - Action videos
 - TV
 - Blowing bubbles
 - Conversation
 - Reading with them
 - Looking at a puzzle books
- Teach self-talk. Some examples of useful self talk include: "This will be over soon", "I can handle this", "It's tough but I am doing well", "This will help me in the long run". Children above about 6 years of age can be coached during a procedure to say calming and relaxing things to themselves. After about age 10 years, children can learn to do this even when a "coach" is not there.

4. RELAXATION IDEAS FOR CHILDREN OF DIFFERENT AGES

Relaxation is a useful way to combat pain. While relaxation techniques can be helpful even the first time they are used, they become more effective for managing pain the more practiced children are in their use. Therefore, we suggest that relaxation techniques be learned in the first couple of weeks, or as soon as possible after the initial diagnosis. That way, the child and their parents will know how to use these techniques when they are really needed. Encourage parents to learn these techniques along with your child - the stress of having a child with arthritis is considerable and many parents find relaxation helpful for themselves.

Babies: relax with rocking, cuddling, sucking on a sweetened soother, gentle stroking, soothing talk, and lullabies.

Toddlers and preschoolers: relax with many of the techniques used for babies. They also enjoy stories, and often love hearing the same one over and over. A favorite teddy bear or blanket is often comforting. Listening to or singing a familiar song may also relax them. Children may play with a toy to distract themselves, relax and forget their worries.

School-age children: often enjoy cuddles and a gentle massage by parents. Favorite comfort objects may also be used, such as a teddy or favorite jumper. Reading may relax some children, while for others it can be a chore. "Pleasant imagery" (such as recalling a favorite activity), or taking deep slow breaths, may be used. From eight years of age children may be able to learn more formal relaxation techniques.

Teenagers: can readily learn formal relaxation techniques such as progressive muscle relaxation, visualisation and deep slow breathing. Many of the techniques used with younger children (cuddles, being read to, massage) will also comfort an older child. Adolescents will also have comfort objects, such as a favorite sweater, a small stuffed toy, or a good luck charm. Listening to music can also be a good relaxing distraction for teenagers.

5. DEBRIEFING AND POSITIVE REINFORCEMENT

It is important to discuss the procedure with the child and parent. Children respond well to praise. Minor misbehavior should be ignored. Small rewards, such as stickers, food treats, or a special activity, can help a child with painful procedures. Rewards should also be given for effort. Painful procedures are difficult, and the child who is trying to co-operate should have as much recognition as the child who is able to achieve it. Avoid bargaining with the child.

6. ASSESSMENT OF PATIENT/FAMILY KNOWLEDGE

Finish the session by going through the assessment of patient/family knowledge tool for module three. Use the questions provided to assess the patient and/or parent level of understanding. Allow time for further questions, discussion and clarification. Encourage patients to practice strategies at home to develop skills in relaxation, breathing etc.

Module Three: Assessment Guide

A guide to assessing patient/family knowledge post module

ASSESSMENT OF KNOWLEDGE (Questions used to encourage patients & parents to demonstrate their knowledge of JIA). Question A = Parent Question B = Child/Young person	PERFORMANCE INDICATORS	ASSESSMENT SCALE 0= Does not understand 1= Needs review 2=Understands well		
9a."Tell me what you will do to help your child manage procedures" e.g. blood test, joint injections, an anaesthetic, injections etc.	1) Check for detailed knowledge of at least one strategy, and how to practice it.	0	1	2
9b." Tell me what you will do to help yourself manage a blood test / joint injection / anaesthetic / needles?"	2) Observe and assist with use of strategy during first procedure. 3) Check against personal procedure plan in detail with both the patient and parents.			

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Module Four: Chronic Pain Management in JIA

The following education module is designed to assist patients and their families to understand how the body feels pain, in order to increase their self-efficacy for managing arthritis pain. It also outlines some useful techniques that can be taught to patients and their families to manage pain associated with JIA. Please utilize the information sheets and worksheets outlined below to support your teachings.

AIMS OF EDUCATION MODULE FOUR

- To provide patients and families with an understanding of the causes and effects of chronic pain in Juvenile Arthritis.
- To provide an understanding of the strategies that are available to manage chronic pain, and for patients to develop skills in using these.

1. SUPPORTING INFORMATION REQUIRED

- Information Sheet – ‘How your body feels pain’
- Worksheet – ‘Ways to help myself feel better when I’m hurting’
- Information Sheets – ‘Breathing and relaxation strategies for kids and teenagers’ and/or ‘Relaxation instructions for parents’

2. WHAT IS PAIN?

Discuss with patients and families:

- The need to learn to manage pain so they can enjoy life despite it.
- Differences between acute and chronic pain.
- What causes pain in JIA (Inflammation and nerve damage/irritation).
- Gate control theory: How pain is felt in the body.
- Use gate control theory as a rationale for using physical (e.g rubbing/tens) and psychological techniques to manage pain.
- Key point: “Changing your awareness changes the pain experience”.

Handout: ‘How your body feels pain’

3. EXPLORE THE COPING STRATEGIES CURRENTLY BEING USED

- Brainstorm with child and parent to develop a list of things they do to manage pain. You may need to prompt and question a lot to elicit these. It is important to generate at least 1 or 2 to create a sense of self-efficacy and clearer understanding of what is meant by ‘coping strategy’. For example: What do you do when you are hurting to help yourself feel better? At home? At school?
- Rate the helpfulness of each strategy for reducing “how much the pain bothers you” out of 10.

4. DESCRIBE PRIMARY/SECONDARY CONTROL MODEL OF COPING

- Describe what Primary and Secondary Control strategies are in lay terms. Talk about research that shows need to use both to manage pain effectively. Emphasise active attempts at coping as essential to managing both the physical and emotional aspects of pain.
- Give examples of Primary and Secondary Control strategies, covering the following categories: Primary (e.g. heat/cold, baths, exercises, TENS, massage, medication, splints, pacing activities and rest); Secondary (e.g. Distraction, Self-soothing, Self-talk, Support seeking, Relaxation and visualisation).
- Apply to coping strategies already listed to illustrate.
- Brainstorm alternatives to create one 'helpful coping strategies' list combining existing and new strategies. Emphasise both Primary and Secondary strategies. Use worksheet template which children can decorate.
- Discuss with parents that their role is to remind children to use strategies – place list on fridge etc.

5. IDEAS TO USE TO GENERATE PERSONALISED COPING STRATEGIES

- Distraction: watch TV, listen to music, play a board game, draw, read, play with your pet, do homework, talk to a friend, help mum or dad around the house, go to the park, do stretching exercises, play a computer game, do something that makes you laugh.
- Self-talk: I'm OK, I can cope with this, It won't last forever, I can do something to make myself feel better, I'll look at my list of coping strategies and pick one to do, remember to breathe, do I need to change my activity?, I'll ask mum for a hug, that will help.
- Self-soothing: Do something which gives you physical comfort and pleasure e.g. have a warm bath, snuggle under a doona, cuddle your mum, cuddle a teddy bear, have a 'treat' like a chocolate or ice-cream and savor every bit of it, rub moisturiser into your skin, or ask someone else to give you a massage, get into a really comfortable spot on the couch or in bed and rest for a while.
- Support seeking: Tell an adult you are feeling sore, sad or worried, ring a friend, ask the teacher to help with an activity in a way that doesn't hurt you, arrange to visit your grandparents, go out with your friends, invite a friend to come to your house, do 'quiet' activities with your friends like watch a movie or play a board game, join a support group like AV and go to their events.

Worksheet: 'Ways to help myself feel better when I'm hurting'

6. DIAPHRAGMATIC BREATHING PRACTICE

Generating ideas for the coping list is generally sufficient to teach children how to use strategies such as basic distraction, self-talk, self-soothing, support seeking and pacing activity. However, instruction in diaphragmatic breathing and visualisation is necessary for successful use of these strategies. Further instruction in visualisation techniques may be completed by parents at home with the aid of a guided relaxation CD, or during a special education session or referral to a psychologist or hypnotherapist.

Diaphragmatic breathing practice instructions:

- Place one hand each on your chest and diaphragm to assess how you normally breathe.
- To practice breathing from diaphragm, put hands behind head and elbows to side while sitting in a chair. Position 'locks' chest, so when breathe normally will notice what it is like to breathe from diaphragm. OR: Visualisation exercises – lie on back and place a hand below belly button. When breathe in imagine filling a balloon inside your abdomen, imagine it deflating when breathe out.
- Observe how often you hold your breath when you anticipate or are experiencing pain. When you experience pain, tension, stress, anxiety or anger, change this experience by breathing. Deliberately stop and pause. Take a slow deep breath from the diaphragm. Think about what you are doing and how you are feeling. What are your choices to manage this situation or your feelings about it?
- To get really good at breathing so it helps the most, you need to practice, just like learning any other skill. Try and practice every day, or even two 10 minute practices a day would be good. Using a relaxation CD or having someone else talk you through it can be very helpful to help you to keep thinking about what you're doing. Our brains have quite short attention spans and will wander often during your practice (to school tomorrow or what's for dinner). When this happens just notice that you've wandered and bring your mind back to breathing. It will get easier each time you practice. Sometimes when we stop to relax we feel the pain more because we've taken away other distractions. This is normal, and won't last long because you are about to distract your attention again by focusing on your breathing and /or a guided relaxation CD. Use the breathing to help you through the pain, instead of getting stressed and anxious and letting the pain stop you from breathing and relaxing.

Handouts: 'Breathing and relaxation strategies for kids and teenagers' and/or 'Relaxation instructions for parents' (depending on the age of the child).

7. ASSESSMENT OF PATIENT/FAMILY KNOWLEDGE

Finish the session by going through the assessment of patient/family knowledge tool for module four. Use the questions provided to assess the patient and/or parent level of understanding. Allow time for further questions, discussion and clarification.

Encourage patients to practice strategies at home to develop skills in pain coping strategies such as distraction and diaphragmatic breathing.

Module Four: Assessment Guide

A guide to assessing patient/family knowledge post module

ASSESSMENT OF KNOWLEDGE (Questions used to encourage patients & parents to demonstrate their knowledge of JIA). Question A = Parent Question B = Child/Young person	PERFORMANCE INDICATORS	ASSESSMENT SCALE 0= Does not understand 1= Needs review 2=Understands well		
10a. "Tell me how your child can use his/her brain to be less bothered by pain"	Check for knowledge of (prompt if necessary): 1) Gate control theory 2) Multidimensional nature of pain	0	1	2
10b. "Teel me how you can use your brain to be less bothered by pain"				
11a. "Tell me how you can help your child manage pain"	Check for parents' knowledge of (prompt if necessary): 1) Both primary and secondary control strategies 2) Ways to encourage their child to use strategies Check for patients' knowledge of (prompt if necessary): 1) Use of both primary and secondary control coping strategies 2) Observe use of diaphragmatic breathing or relaxation technique			
11b. Tell me what you would do to help yourself feel better if you get sore at home? At school?				