

# Healthier Ever After

Everyday tips  
for living with  
autoinflammatory  
diseases

Brought to you by the  
Autoinflammatory Alliance



# introduction

People diagnosed with autoinflammatory diseases are often prescribed medications that have to be injected beneath the skin in order to help control their disease. These medications help to manage symptoms day-to-day and also may help prevent long-term complications.

When starting an injectable medication routine, it's important that patients and their caregivers learn how to give these injections from a doctor or nurse. However, it's also normal for all of those involved to have a lot of questions. Most people are unfamiliar with administering, storing, and managing injectable medications, so the process can seem overwhelming.

This booklet is designed to further educate and facilitate the injection process, especially when treating children. These tips were written by the Autoinflammatory Alliance with the help of parents, patients, and healthcare professionals.

The Autoinflammatory Alliance is dedicated to improving awareness, care, and treatment for patients with Cryopyrin-Associated Periodic Syndromes (CAPS), such as: NOMID/CINCA, Muckle-Wells, FCAS, and other autoinflammatory diseases.

Please visit [www.autoinflammatory.org](http://www.autoinflammatory.org) to learn more about autoinflammatory diseases, treatment options, and how to connect with other patients and caregivers. You can also download informational literature about these conditions.

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## General considerations

Please review all prescribed, over-the-counter medications, and the plan of care with your doctor before you begin a new medication routine. The materials in this booklet are meant to help support caregivers and patients with the injection process, but individual responses to treatment and side effects from various medications may differ from patient to patient.

All prescription injectable medications used to control autoinflammatory diseases have some side effects and may lead to lowering patients' ability to fight other diseases. It's important for you to discuss the potential complications and side effects, and how best to monitor disease symptoms with your doctor.

# explaining the need for injection

## Explain to your child that getting their injection is necessary to help them feel better.

Tell them that many people need medicines for different conditions, and that they need their medication to help them grow strong and healthy.

## Don't make promises that the medication will be a cure.

Instead, explain that this is a lifelong disease and that they will always need some kind of medicine to help them feel their best.

## Building a routine is key.

Make sure they understand from early on that the medicine needs to be given on a regular basis (as ordered by the doctor).

## Fluctuations in behavior are normal.

There may be times when children are okay with their injection routine and later put up a fight. Explain to them that their medicine is working behind the scenes to keep them feeling healthy.

# setting your routine

- **Make sure your child understands** that the injection has to be given routinely so the medicine can work best
- **Injections are something they should get used to doing** as part of their routine, like brushing their teeth or taking a bath
- **Set up a routine by choosing a place and time** you will give the injections. Avoid using the children's bedroom or playroom; they should have "safe places" where they know that they won't be injected
- **Don't take the child to the designated area until you have everything for the injection ready.** Setting up in front of your child may make them anxious and uneasy
- **Try to give injections before an activity your child enjoys.** You can use the activity as a reward for them to look forward to after the injection

# routines on the road

Once you have established your injection routine, you may be ready to travel or plan outings. In fact, children often feel more stable and healthy after starting their medication routine so families can enjoy more activities and adventures. Use these tips to keep your injection routine on the road.

## preparing for travel

- **Order enough medication** so you'll have what you need for the trip, and for when you return. These are special-order medications and it can take longer to get a prescription filled
- **Pack a few days' worth of medication beyond your expected travel time** in case there are delays in getting home
- **Get a small Sharps Container from the pharmacy** or bring a thick plastic container with a lid that securely fastens to store the used syringes
- **Make sure the prescription order is on the medication box.** Also bring a letter written by the prescribing doctor authorizing you to carry these medications on board a plane, or to travel outside the country



### key travel tips

Medication should be refrigerated (or on ice) at all times

Keep the medication at a stable temperature; make sure it's not frozen or left in the hot sun

When flying, pack medications in your carry-on bag, NOT in your checked baggage

## keeping it cold

- **Buy an insulated, easy-to-carry ice chest** or cooler bag with a shoulder strap and an outside pocket for alcohol wipes and bandages for your trip
- **Freeze long-lasting ice packs** from the pharmacy or a sporting goods store to put inside the cooler. Put the ice packs in individual freezer bags to prevent any leaks if they break
- To keep your medication dry, **place each box in a large (gallon size) re-sealable freezer bag and shut securely**
- **Pack extra re-sealable freezer bags** in case your ice packs start to warm up. You can ask for ice to fill your re-sealable bags at most restaurant or fast food places
- **Check your medication's prescribing information** to see the correct temperature for storing the injections. Purchase a small refrigerator thermometer to monitor the temperature in the cooler
- **Try to reserve hotels with a refrigerator in the room.** Make sure that it's plugged in, turned on, and cold when you arrive in the hotel, or when you put the medication into it
- If for any reason you're unable to keep the medication cold or refrigerated, **check with your doctor on how long the medication can stay at room temperature** and still be safe to use

# overcoming injection anxiety

- **Find a low-stress time to inject**, possibly when both parents are available to help out
- **Project a positive, reassuring, and calm attitude** when talking about and giving the injections. Don't make injections a big deal or apologize for having to give the shot
- **Be consistent with your child's injection routine** and make sure to hug and praise your child after the injection
- **It's important to give your child time to talk about their injections.** Ask them how they feel about the injection and discuss issues that may come up

Parents are essential to helping their children navigate negative feelings around their disease. Setting up an injection routine and taking the time to discuss the process may help to reduce injection anxiety. If your child is still expressing fear and concern about injections and/or their disease, talk to their doctor about how to manage these issues.

## reducing pain and discomfort

**Be open with your child when explaining** that the injection may be painful, but that it won't last very long. Sometimes the injection site may become pink or raised, even days after the injection was given. This is a common and minor side effect, especially in the first month of starting the injections.

**Topical sprays or creams** are another pain-reducing option to discuss with your doctor. These only relieve the initial pain of the needle pricking the skin, but they don't reduce pain in the deeper tissues.

Some children like to have **EMLA® cream** applied to the area to reduce injection pain. This cream must be applied at least an hour before giving the injection and must be approved and ordered by your doctor.

**Review the medication instructions** with your doctor or pharmacist to see if it is safe to let the medication sit out at room temperature before the injection. Some patients find that the injection of the medication is less painful if it is not too cold.

### \* product suggestions

Some parents have found that these products can help ease the pain of injection:

**ShotBlocker®**: [bionixmed.com/MED\\_Pages/ShotBlocker](http://bionixmed.com/MED_Pages/ShotBlocker)  
**Buzzy®**: [buzzy4shots.com](http://buzzy4shots.com)

Trademarks are the property of their respective owners.

# distracting during the injection



Give your child age-appropriate sensory toys, especially ones with textures and colors that they can squeeze or bite safely.

**Tell them a story in a calm, confident voice while keeping their eyes away from the shot site.**

**Keep talking and listening to your child about how the shot feels and how it can go better next time. Encourage verbal children to share ideas on how to make the injection better.**

Sing a song or have a musical toy for your child to hold. Some children also like to blow on a pinwheel, harmonica, or other musical instrument to distract them during the injection.

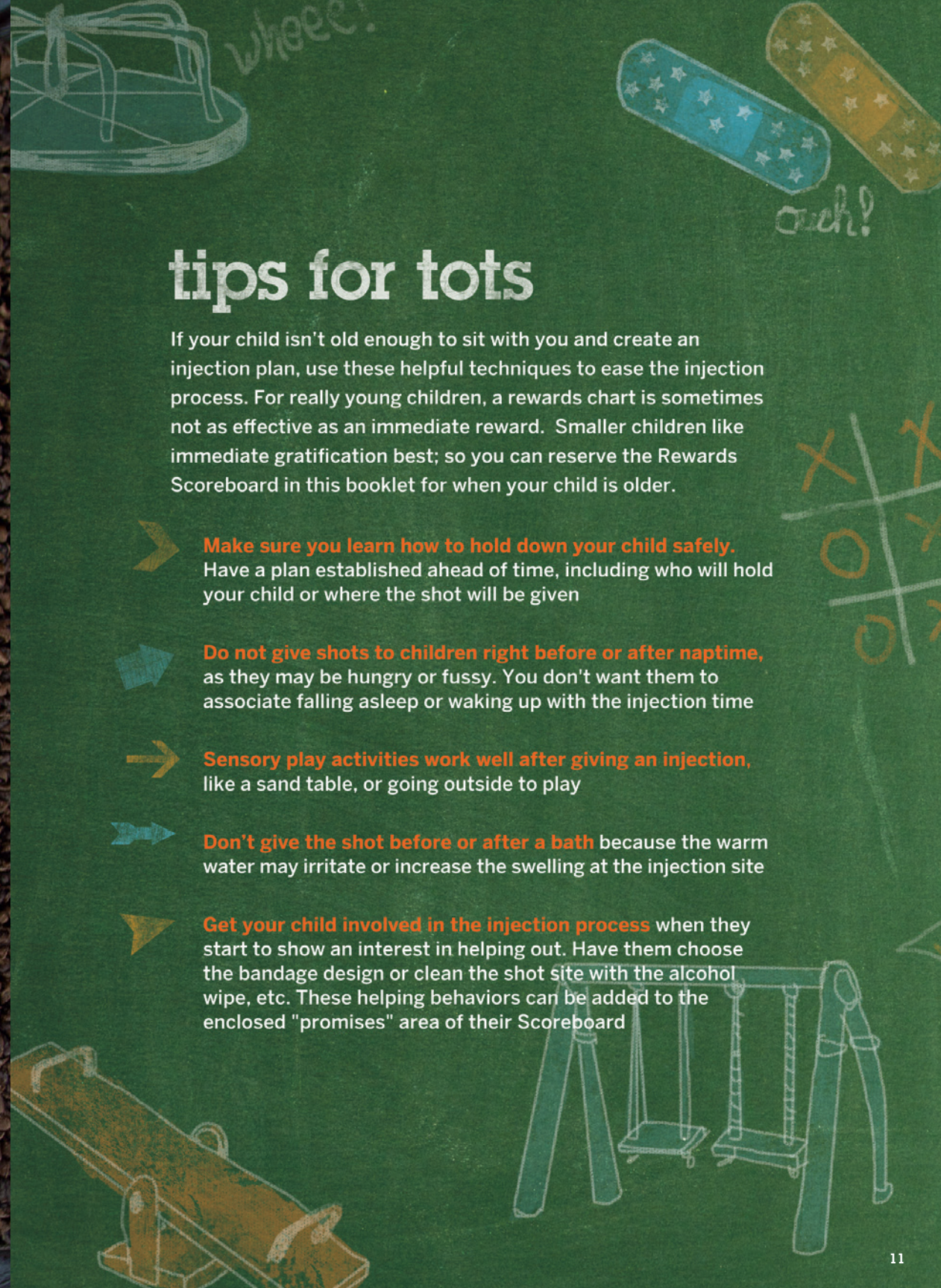
Consider buying a toy doctor kit that includes a pretend syringe to have your child role-play giving the injection to their dolls or stuffed animals.

**Older children can skim through a book, listen to music, or watch cartoons while the shot is being given.**

## tips for tots

If your child isn't old enough to sit with you and create an injection plan, use these helpful techniques to ease the injection process. For really young children, a rewards chart is sometimes not as effective as an immediate reward. Smaller children like immediate gratification best; so you can reserve the Rewards Scoreboard in this booklet for when your child is older.

- **Make sure you learn how to hold down your child safely.** Have a plan established ahead of time, including who will hold your child or where the shot will be given
- **Do not give shots to children right before or after naptime,** as they may be hungry or fussy. You don't want them to associate falling asleep or waking up with the injection time
- **Sensory play activities work well after giving an injection,** like a sand table, or going outside to play
- **Don't give the shot before or after a bath** because the warm water may irritate or increase the swelling at the injection site
- **Get your child involved in the injection process** when they start to show an interest in helping out. Have them choose the bandage design or clean the shot site with the alcohol wipe, etc. These helping behaviors can be added to the enclosed "promises" area of their Scoreboard





# making your injection plan



**It's important that you and your child work as a team** and create a plan to manage the injection process. Talking about, and participating in the plan, will engage children and allow them to understand the need for injections.

**From time to time, ask them what they think about before, during, and right after they get their injection.** This enables you to stay informed and to understand what makes your child comfortable, so you can make adjustments as their needs change.

**When you're ready to start, sit with your child and fill out the simple guidelines on the next page.**



## my injection plan

① How do you want to help us get ready for the injections? (For example: clean the injection site, pick out my bandage, etc) \_\_\_\_\_

② What places will be "injection-free zones"? (For example: playroom, bedroom, kitchen) \_\_\_\_\_

③ Which place will be used as the injection zone? (Choose a place that is not used often, or a specific piece of furniture in a room) \_\_\_\_\_

④ Do you want to sit up or lay down for the shot? \_\_\_\_\_

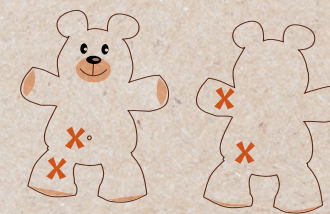
⑤ Choose the person who will give the injection to you: \_\_\_\_\_

If they aren't there, who else can give you the shot? \_\_\_\_\_

⑥ The shot has to be given in different parts of my body, but the places I like best are: (rank #1-4)

Tummy \_\_\_\_\_ Upper Arms \_\_\_\_\_

Bottom \_\_\_\_\_ Upper Legs \_\_\_\_\_



⑦ What do you want to do while you are getting the injection? (For example: count to three, sing a song, tell a story, or be quiet)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

⑧ Are there other things you want me to know about when you get injections?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



# keeping score

After creating the injection plan together, you and your child can develop the Rewards Scoreboard. This scoreboard system rewards good behavior before and during injections. The board consists of a series of promises and rewards designed to ease the injection process and ensure your child sticks to the plan.

### It's simple to use:

1. First, decide together what promises need to be completed each time the injection is given (for example: picking out their bandage, not screaming during the shot, etc).
2. Each day that your child completes all of their promises, they will earn one good behavior sticker to put on the chart.
3. Once your child gets a set amount of stickers, they'll earn a reward that you'll have chosen ahead of time.

Inside this booklet we've included a reusable Rewards Scoreboard and stickers to keep track of your child's good behavior. See the next page for an example of a completed board to work from.

Make sure to create rewards that fit your budget and time constraints. It's best not to use food as a reward, but it could be a part of the experience, such as getting popcorn at the movies.



sample scoreboard

# my rewards scoreboard

for the month of:

# OCTOBER

Put a sticker on the calendar for every day your child completes their promises.

sun	mon	tues	wed	thurs	fri	sat
29	30	1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31		

### my promises

I will	I won't
<i>Pick out my band-aid</i>	<i>Run away from mommy</i>
<i>Choose my injection spot</i>	<i>Scream during the shot</i>
_____	_____
_____	_____
_____	_____

### my rewards

Decide the number of stars needed to earn each reward.

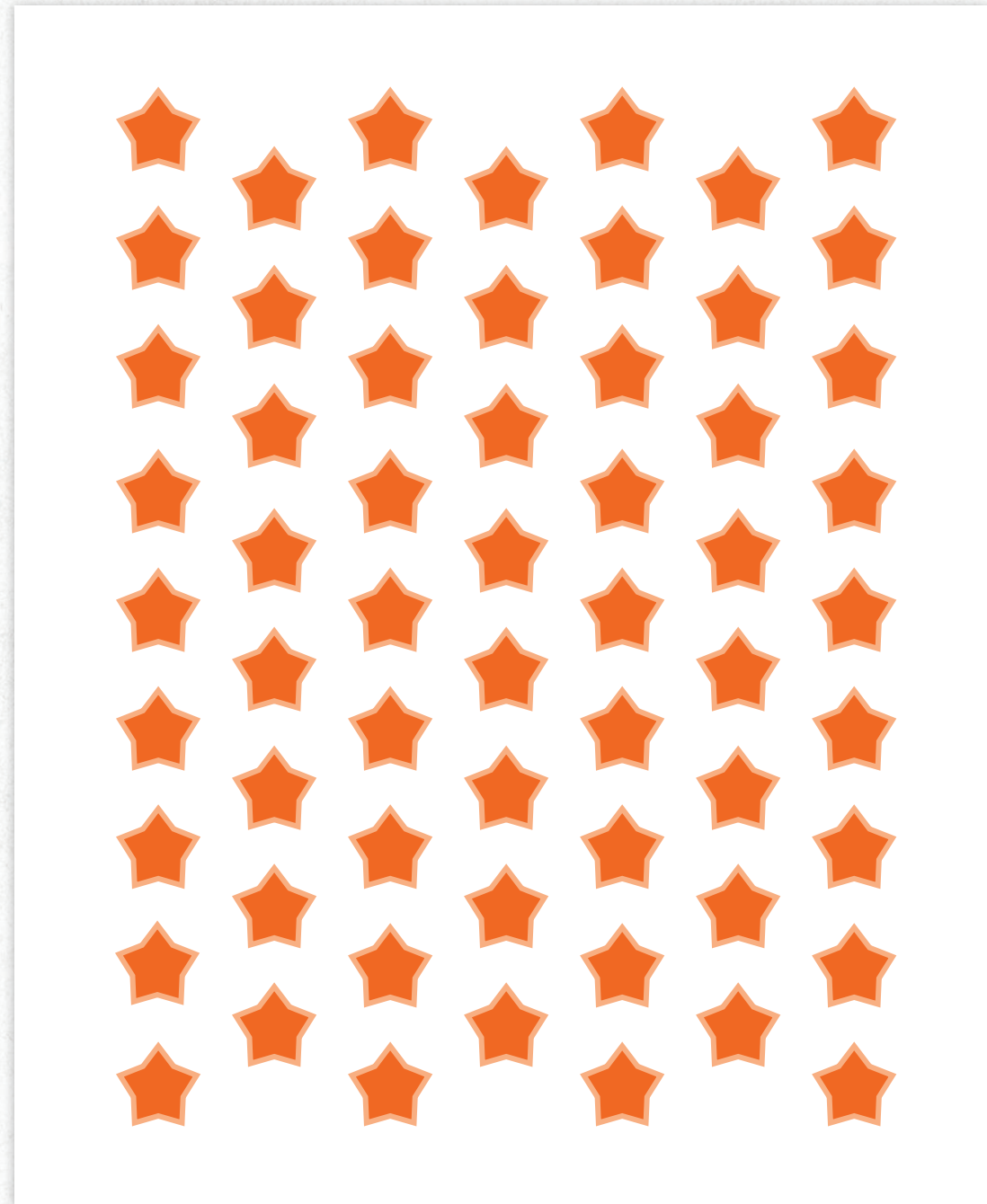
<u>5</u>		<i>Going to the park</i>
<u>15</u>		<i>Trip to the movies</i>
<u>30</u>		<i>A new video game</i>





Notes:

A series of horizontal dotted lines for writing notes, spanning the width of the page.



your rewards  
scoreboard inside!

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[autoinflammatory.org](http://autoinflammatory.org)

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Designed by The CementBloc



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