

## Welcome to Kineret



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## Introduction

This booklet has been given to you because you, or someone in your care, has been prescribed Kineret.

Your doctor probably has already told you about the condition that Kineret is being used to treat.



Coming to terms with a diagnosis for an illness you may have never heard of can be challenging and difficult for your whole family. But starting treatment is the first step to bringing relief to the symptoms and managing life ahead.

Although the information in this booklet will cover what you need to know about injecting Kineret, your doctor or nurse will only encourage you to do this when they feel you are ready and confident.

Take your time reading through the pages that follow. Starting a medicine that requires injections will seem daunting at first – but thousands of people do this every day. And when you know the benefits it brings, you are likely to find that it can become part of your routine too.

If you come across an unfamiliar word or medical term, turn to the back pages where you will find some helpful definitions

Everybody is different and your doctor or nurse is best placed to answer any specific questions about the diagnosis and management in your particular situation

## What is Kineret?

Kineret is a solution which is given by an injection under the skin. Kineret is the brand name for a product called **anakinra** and doctors will sometimes use this name. The medicine belongs to a category of drugs known as ‘human interleukin 1 receptor antagonists’; these are man-made proteins that are almost identical to proteins that are naturally found in the body. They are sometimes referred to as IL-1 antagonists or IL-1Ra, but we will just call it Kineret from here!

Kineret works by blocking the protein (interleukin-1) that is overproduced because of the underlying disease. This protein, which is normally controlled by another natural protein, encourages inflammation. By controlling the inflammation, Kineret reduces the disease symptoms and helps to protect against long-term complications. Kineret acts in the same way as the natural interleukin-1 blocking protein.

Don't worry if this all seems complicated! You don't need to understand the science to get the best out of a medicine. Your doctor and their team are the experts - you can rely on them to advise on what's right in your case



## What sort of conditions is Kineret used for?

Kineret is used to manage a range of conditions including several that are known collectively as CAPS or Cryopyrin-Associated Periodic Syndromes to give them their full name. Your doctor may have used a more precise definition and the chart below summarises some of these.

<b>CAPS or Cryopyrin-Associated Periodic Syndromes is a collection of conditions including:</b>	
<i>Condition</i>	<i>Symptoms</i>
FCAS Familial cold auto-inflammatory syndrome	Fever spikes of short duration caused by being exposed to cold Raised rash Joint pain (arthralgia)
MWS Muckle-Wells syndrome	Fever Recurrent episodes of raised rash Joint pain (arthralgia) Malaise Hearing loss in later years Amyloidosis (when abnormal proteins are deposited in tissues in the body)
NOMID Neonatal Onset Multi-system Inflammatory Disease  also known as  CINCA Chronic Infantile Neurological Cutaneous and Articular syndrome	Fever <b>Cutaneous</b> Raised rash which starts soon after a baby is born <b>Neurological</b> Changes to the nervous system which vary in severity and can impair normal daily activities and cause various levels of disability. These include: - Learning disabilities - Non-infective meningitis (inflammation of the protective membranes covering the brain and spinal cord) - Increased pressure in the brain - Papilloedema (swelling at the back of the eye) - Cerebral atrophy (reduced size of the brain) - Hearing loss <b>Articular</b> - Chronic inflammatory arthropathy (inflammation in the joints) - Skeletal dysplasia (short height) - Unusual body or facial features

## Getting started on Kineret

Injecting at home can seem like a challenge – but it will get easier once you get more experienced. And you will always be given training by qualified healthcare professionals to make sure you feel confident in the process.

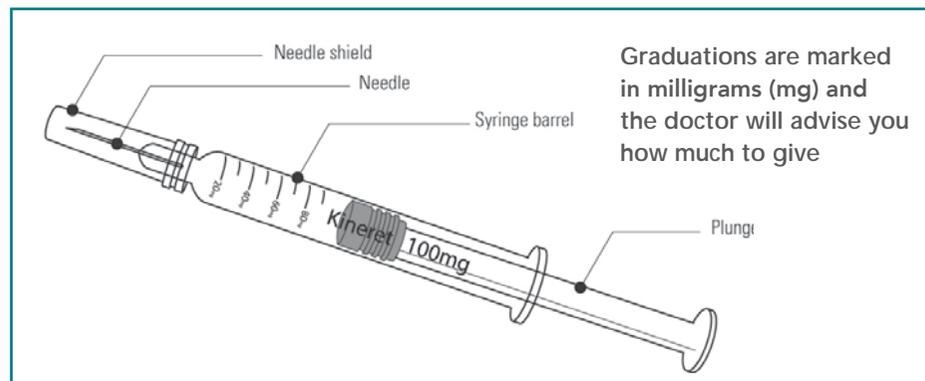
### What does Kineret look like?

The Kineret pack contains 7 or 28 syringes that need to be kept in the fridge.

Each syringe is prefilled with Kineret so there is no need to mix anything. It is ready to go.



The syringe is 'graduated' – the marks on the side to help you give the right amount. **You need to make sure, particularly for children, that it is the graduated Kineret syringe you use.** This will allow you to get the dose correct.



Inside the syringe is a clear, colourless-to-white solution which may contain some white particles.

### How much Kineret is needed?

Your doctor will work out what dose is right for you (or your child). It depends on weight and the severity of the symptoms and so may change over time.

## When should Kineret be given?

Kineret is given daily. It is an injection that goes under the skin. It's a good idea to give the injection at the same time every day.

### What do I do when I am ready to inject?

Find a well-lit, comfortable, clear and clean area where you have enough space to have all the equipment you need within reach.

Wash your hands thoroughly.

You will then need;

1. Kineret prefilled graduated syringe(s)
2. Alcohol wipes
3. A sterile gauze of tissue

Make sure you will be able to dispose of any elements in the way your doctor or nurse advised before you go any further.

Remember to keep the remaining syringes in the fridge

Do not shake the syringe. If it seems foamy, allow a few minutes for the solution to clear

Make sure the alcohol wipe is easy to remove from the packaging as you will have a syringe in your hand when you wipe the skin

### How do I check the Kineret is in good condition?

Check the expiry date on the pre-filled syringe label (look for letters EXP). Don't use the syringe if the date is after the end of the month shown.

Check the appearance of liquid in the syringe. It must be a clear, colourless-to-white solution. There may be some translucent-to-white particles in the solution. Don't use the syringe if the solution is discoloured or cloudy, or if any particles other than translucent-to-white ones can be seen.

## Getting the injection ready

### Should I inject straight away?

For a more comfortable injection, take the syringe out of the fridge 30 minutes before you intend to give it. Make sure it is in a safe place out of the sight and reach of children and allow it to warm to room temperature. Alternatively you can hold the pre-filled syringe gently in your hand, warming it for a few minutes. Don't warm Kineret in any other way (for example, do not warm it in a microwave or in hot water).

**Don't** remove the cover from the syringe until you are ready to inject.

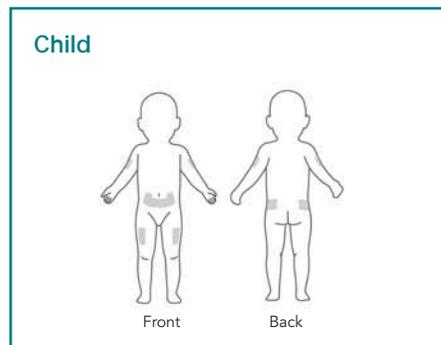
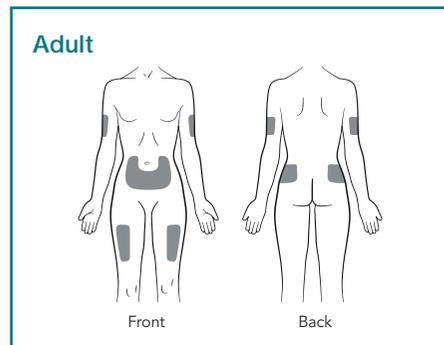
### Where should I inject?

The most suitable places to inject are;

- the abdomen (except for the area around the navel)
- the top of the thighs (this is especially good for infants under a year if they have slightly chubby legs)
- the upper outer areas of the buttocks\*; and
- the outer area of the upper arms\*.

\* Only really suitable if someone else is giving you the injection

**Change the place that you inject each time so one area does not become sore**

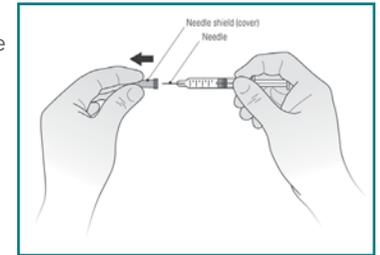


- Don't inject into skin that is tender, red, bruised, or hard
- Avoid scars or stretch marks
- Don't inject close to a vein

## Preparing the dose

### Ready to inject?

Before you inject Kineret you need to hold the syringe barrel and gently remove the cover from the needle without twisting. Pull straight as shown. Don't touch the needle or push the plunger. Discard the needle cover straight away.

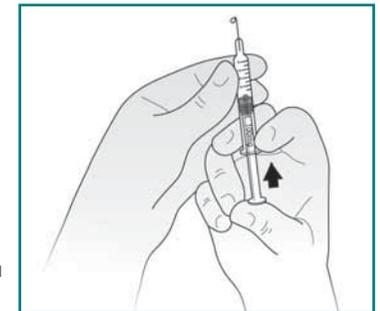


You may notice a small air bubble in the pre-filled syringe. You don't have to remove the air bubble before injecting. Injecting the solution with the air bubble is harmless.

**IF YOU ARE USING LESS THAN 100mg - THAT IS LESS THAN ALL THE SOLUTION IN THE SYRINGE - YOU WILL NEED TO DISCARD SOME OF THE LIQUID**

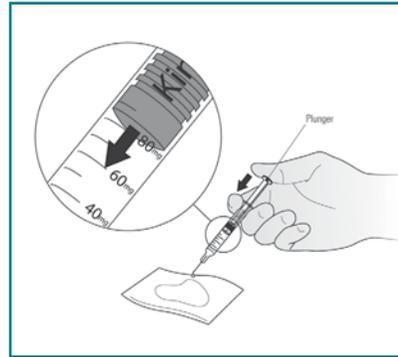
To do this:

Hold the syringe in one hand with the needle pointing straight upwards as shown here. Put your thumb on the plunger rod and push slowly until you see a tiny liquid drop at the tip of the needle.



Turn the syringe so that the needle is now pointing downwards. Place a sterile gauze or tissue on a flat surface and hold the syringe above it with the needle pointing towards the gauze or tissue, as shown.

Put your thumb on the plunger rod and push slowly until the front end of the plunger has reached the mark on the graduated scale of the recommended dose. The extra liquid will be absorbed by the gauze or tissue as shown. Now the correct dose is ready to be injected.



**Make sure the needle does not touch the gauze or tissue**

**If you are not able to set the correct dose or if you drop the syringe, dispose of it and use a new one. This just means going to the next box earlier, so remember to order your next supply earlier too**



## Giving an injection

### How do you give the injection?

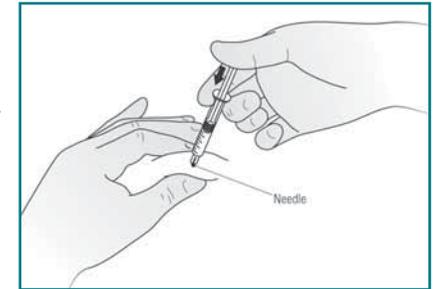
Disinfect the skin with the alcohol wipe and let it dry off naturally in the air (this only takes a few seconds). Then pinch the skin between your thumb and forefinger, without squeezing.

Put the needle fully into the skin as shown by your nurse or doctor.

Inject the liquid slowly and evenly, always keeping the skin pinched.

After injecting the liquid, remove the needle and let go of the skin.

You can hold a little cotton wool or tissue over the injection site.



**Only use each syringe for one injection. Do not reuse a syringe as this can cause infection. Any unused medicine must be discarded**

### What to do with the used syringe and other items

Don't put the cover back on the needle of the syringe.

Keep used syringes out of reach and sight of children.

Never put the pre-filled syringes that you have used into your normal household rubbish bin.

If you used a dose lower than 100 mg you will have liquid from the syringe on a gauze or tissue. Discard the wet gauze or tissue with your syringe and clean the surface with a fresh tissue.

The used syringe and any gauze or tissue with Kineret solution on them should be disposed of as the doctor, nurse or pharmacist advised. If you have medicine you no longer need, ask the pharmacist what you should do – this will help to protect the environment.



## Glossary of terms

Abdomen	Tummy or belly
Alcohol wipe	Disinfectant in a disposable cloth
Amyloidosis	When abnormal proteins are deposited in tissues in the body
Antihistamine	When used in a cream, ointment or tablet reduces swelling and irritation
Arthralgia	Joint pain
Arthropathy	Disease of the joint
Barrel	Central tube on syringe
Buttocks	'Bum'/bottom (fleshy part below the spine)
CAPS - Cryopyrin-Associated Periodic Syndromes	A name for a collection of rare conditions which cause episodes of, or continuous, inflammation
Cerebral atrophy	Reduced size of the brain
Chronic inflammatory arthropathy	Inflammation in the joints which continues for a long time
CINCA - Chronic Infantile Neurological Cutaneous and Articular syndrome	A rare condition which results in unprovoked sustained episodes of inflammation (see p5)
Corticosteroid	When used in a cream or ointment, reduces inflammation
Dose	Quantity of medicine
Expiry date - EXP	The last date a medicine should be used
FCAS - Familial cold auto-inflammatory syndrome	A rare condition which causes episodes of inflammation commonly triggered by exposure to cold (see p5)
Fever	Raised body temperature
Graduated	The marks on the side of the syringe to show how much medicine to give
Healthcare professional (HCP)	Doctor, nurse or pharmacist
Human interleukin-1 receptor antagonists	A man-made protein used as a medicine to block the natural interleukin-1 which causes inflammation
Injection site	Place where the injection is given
Inflammation	Area of the body which shows signs of pain, redness, heat, swelling and may have loss of function
Interleukin 1 receptor	A protein that is naturally found in the body which when activated triggers inflammation
Kineret	Brand name for a product called anakinra; a drug in a group known as 'human interleukin 1 receptor antagonists'
Malaise	A feeling of general discomfort or being unwell
Meningitis	Inflammation of the protective membranes covering the brain and spinal cord
MWS - Muckle-Wells syndrome	A rare condition which causes unprovoked episodes of inflammation (see p5)
NOMID - Neonatal Onset Multi-system Inflammatory Disease	A rare condition which results in unprovoked sustained episodes of inflammation (see p5)
Papilloedema	Swelling at the back of the eye
Particle	Small object
Pharmacist	Chemist
Plunger	The rod that is pushed into the syringe to push medicine out
Pre-filled syringe	A syringe which comes with medicine already in



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