

Cosentyx[®] (secukinumab) Patient Pack: Hidradenitis suppurativa

This leaflet does not replace the Patient Information Leaflet (PIL) that comes with your medication, or advice from your doctor or nurse. Always read the PIL before starting your treatment and use Cosentyx exactly as your doctor or nurse has described.

 **Cosentyx[®]**
secukinumab

This patient support pack has been funded and developed by Novartis Pharmaceuticals UK Ltd.

Please find full information on how to report a side effect [here](#).

This pack is intended for patients who have been prescribed Cosentyx for their active moderate to severe hidradenitis suppurativa (acne inversa).

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Welcome to Your Cosentyx

You have been signed up to **Your Cosentyx** because you have been prescribed Cosentyx to treat your moderate to severe hidradenitis suppurativa (HS).

Your Cosentyx is a personalised service, designed to support you while taking your medicine, which includes:



- **This patient pack**
Contains information to get going with your medicine and to help you get the most out of your treatment



- **Your Homecare**
You will get Cosentyx autoinjector[®] pens delivered straight to your door, and a home visit from a Homecare nurse



- **Your Homecare support line**
A support line for arranging your medicine deliveries and Homecare nurse visits



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Your Cosentyx journey

Your hidradenitis suppurativa

Whatever your experience with treatments, the information in this chapter will help you to better understand your condition, what causes it and how it can be treated.

Your medication

This chapter explains what you need to know as you get started with your medication.

Your injections

This step-by-step guide will take you through how to administer your medicine correctly.

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Your wellbeing

Living with a long-term condition and managing both your treatment and day-to-day life can be a challenge. The helpful hints and advice in this chapter will help you stay relaxed and in control.

Your travel plans

This chapter contains tips for travelling with your medicine.

Your sources of support

Staying on top of your condition can be easier when you know about the resources that are available to help you. 'Your sources of support' shows you where you can go for more information about your treatment and living with HS.

Frequently asked questions

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Your treatment journey



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Homecare Provider

You don't need to do anything!
You'll hear from us within 48 hours to arrange your first delivery and nurse visit at a time that suits you.
We'll explain how to store your medicine.
We'll also run through the benefits of your support programme and make sure you have the **Your Homecare support line** number.

Medication Delivery

We can work with you to deliver at a convenient time to your verified address, where someone can put your medicine in the fridge. Delivery times can be changed via **Your Homecare support line** to fit around you.
With your first delivery, you'll also receive this **patient pack** complete with sharps bin and alcohol swabs.

Homecare Nurse

Your nurse will contact you to arrange your first dose (and they'll also call you when they are on their way).
The nurse will help you get the right injection technique, answer any questions and ensure you have all the resources you need (this **patient pack**).
Up to two follow-up visits are available if you need them.

Reminders

If you want, you will always be reminded about treatment day or appointment.
Choose from text, email or phone call.



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Registration

You opted to be registered when you were initially prescribed Cosentyx, giving you the option to benefit from the support service.

Your Homecare Support Line

Need to change a delivery or appointment?
No problem, speak to a member of the **Your Homecare support line** team.

Patient Pack

We provide a wide range of information and resources along with the first delivery.
This will help you get the most from your medicine, whether you are at home or travelling.

Your Homecare

Your Homecare is intended to make your treatment as convenient for you as possible. The service includes:

Deliveries

You will have your Cosentyx UnoReady® pens delivered at a time and appropriate address that suits you. This is important because your medicine needs to be kept cool in a fridge, between 2°C and 8°C (see the **Your medication** chapter for more information about how to store your medicine).

If someone else is receiving your delivery for you, you should let them know that they will need to sign for it and then store it as explained above.

Call **Your Homecare support line** to arrange your deliveries. We can deliver to your home, work or any other UK residential address.

On this call, you will be able to log your preference for text or email reminders. You can then receive a text or email confirming your delivery details.

If you need to change a delivery time or location, you will need to call the **Your Homecare support line**.

Nurse visit

Before you begin using your medication, you will have a visit from a Homecare nurse. This will give you a chance to ask any questions you have about your medicine and make sure you are completely comfortable with the self-injection technique.

Your Homecare support

To organise your next Homecare delivery, or if you have any questions about your next delivery or nurse visit, please call the **Your Homecare support line**.



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Your hidradenitis suppurativa

A guide to your condition

The information provided in this booklet is not intended to replace conversations with your doctor, but could help improve your understanding of hidradenitis suppurativa (HS) so that you can make the most of those conversations.

What is hidradenitis suppurativa?

HS is a non-contagious skin condition that affects approximately 1% of the UK population.

HS tends to be more common in women than men and most often develops in patients around puberty. The number of people affected varies between countries due to various factors including ethnicity. It can appear in various forms and symptoms may include comedones (blackheads), tender nodules (lumps) and abscesses (boils) that may leak pus.



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About hidradenitis suppurativa

HS can be persistent with physical symptoms lasting for months and, in some cases, these symptoms may reoccur.

HS can also have an emotional impact.

HS can occur in almost any skin area, but is most common in the area under the breasts, the armpits, inner thighs, groin and buttocks. Scarring may also occur in these affected areas.

While you probably already know a lot about your HS, learning more may help you feel more in control of the condition.

What causes hidradenitis suppurativa?

The cause of HS is unknown, but it is thought that the symptoms occur because of blocked hair follicles.

This blockage means that fluid or pus in the nodules and lumps cannot escape, causing the follicles to swell and burst leading to inflammation and infection.



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How is the severity of hidradenitis suppurativa assessed?

The severity of your HS will influence the treatments you are prescribed. While there are several tools available, your doctor may not use all of these scales. Knowing what you score on one or two of them, will be enough for your doctor.

International Hidradenitis Suppurativa Severity Score System (IHS4)

HS severity is calculated based on the number of lesions (nodules, abscesses or tunnels) and then multiplied by their respective scores (1, 2 or 4). Total IHS4 score is used to define the severity of the disease: 3 or less is mild, a score of 4–10 is moderate and a score of at least 11 is severe disease.

Hurley

Hurley staging classifies patients into three stages: the first is single or multiple abscesses without tunnels, the second is recurrent abscesses with single or multiple tunnels with widely separated lesions and the third is wide spread involvement or multiple interconnected

tunnels and abscesses across the entire area. These three stages represent mild, moderate and severe disease.

Dermatology life quality index (DLQI)

Your doctor may also consider the effect that your HS has on your daily life. The DLQI is a questionnaire that examines the effect that HS has on symptoms and feelings, daily activities, leisure, work and school, personal relationships and treatment. You can complete the DLQI yourself at home. The DLQI is scored from 0 to 30 with higher scores reflecting a greater effect of HS on your life.



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Your medication

A guide to your Cosentyx treatment, how to use it and what to be aware of during treatment

You have been prescribed this medicine to treat your moderate to severe hidradenitis suppurativa.

In this chapter you will find details of where you can find important information that you will need to be aware of before you start your treatment, and information on how to use and store your medicine.

What you need to know before you use your medicine

The patient information leaflet that comes with your medicine contains important information that you should read carefully before you start treatment and keep handy for future reference.

The information in the leaflet includes:

- What Cosentyx is used for
- When it should not be used
- Warnings and precautions
- Signs of infection and allergic reactions
- Using this medicine if you have (an)other condition(s)
- Dosing information
- Possible side effects



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Possible side effects

Like all medicines, this medicine can cause side effects, although not everybody gets them.

Serious side effects

Stop using your medication and tell your doctor or seek medical help immediately if you get any of the following side effects.

Your doctor will decide if and when you may restart the treatment.

Possible serious infection – the signs may include:

- Fever, flu-like symptoms and night sweats
- Feeling tired or short of breath, or cough which will not go away
- Warm, red and painful skin, or a painful skin rash with blisters
- Burning sensation when passing urine

Serious allergic reaction – the signs may include:

- Difficulty breathing or swallowing
- Low blood pressure, which can cause dizziness or light-headedness
- Swelling of the face, lips, tongue or throat
- Severe itching of the skin, with a red rash or raised bumps



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Other side effects

Most of the following side effects are mild to moderate. If any of these side effects become severe, tell your doctor, pharmacist or nurse.

Very common (may affect more than 1 in 10 people):

- Upper respiratory tract infections with symptoms such as sore throat and stuffy nose (nasopharyngitis, rhinitis)

Common (may affect up to 1 in 10 people):

- Cold sores (oral herpes)
- Diarrhoea
- Runny nose (rhinorrhoea)
- Headache
- Nausea
- Fatigue

Uncommon (may affect up to 1 in 100 people):

- Oral thrush (oral candidiasis)
- Signs of low levels of white blood cells, such as fever, sore throat or mouth ulcers due to infections (neutropenia)
- Infection of the external ear (otitis externa)
- Discharge from the eye with itching, redness and swelling (conjunctivitis)
- Itchy rash (urticaria)
- Lower respiratory tract infections
- Abdominal cramps and pain, diarrhoea, weight loss or blood in the stool (signs of bowel problems)
- Small, itchy blisters on the palms of hands, soles of feet and edges of the fingers and toes (dyshidrotic eczema)
- Athlete's foot (tinea pedis)

Rare (may affect up to 1 in 1000 people):

- Severe allergic reaction with shock (anaphylactic reaction)
- Redness and shedding of skin over a larger area of the body, which may be itchy or painful (exfoliative dermatitis)
- Inflammation of small blood vessels, which can lead to a skin rash with small red or purple bumps (vasculitis)

Not known (frequency cannot be estimated from the available data):

- Fungal infections of the skin and mucous membranes (including oesophageal candidiasis)
- Painful swelling and skin ulceration (pyoderma gangrenosum)

For more information on the possible side effects of Cosentyx, please refer to the patient information leaflet included with your medicine or speak to your doctor, pharmacist or nurse.

Reporting of side effects

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at yellowcard.mhra.gov.uk. By reporting side effects you can help provide more information on the safety of this medicine.



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What you need to know before you use Cosentyx

Do not use Cosentyx:

- If you are allergic to secukinumab or any of the other ingredients of this medicine
- If you have an active infection which your doctor thinks is important

If you think you may be allergic, ask your doctor for advice before using Cosentyx.

Warnings and precautions

Talk to your doctor, nurse or pharmacist before using Cosentyx:

- If you currently have an infection
- If you have long-term or repeated infections
- If you have tuberculosis
- If you have ever had an allergic reaction to latex
- If you have an inflammatory disease affecting your gut called Crohn's disease
- If you have an inflammation of your large intestine called ulcerative colitis

- If you have recently had a vaccination or if you are due to have a vaccination during treatment with Cosentyx
- If you are receiving any other treatment for psoriasis, such as another immunosuppressant or phototherapy with ultraviolet (UV) light

Inflammatory bowel disease (Crohn's disease or ulcerative colitis)

Stop using Cosentyx and tell your doctor or seek medical help immediately if you notice abdominal cramps and pain, diarrhoea, weight loss, blood in the stool or any other signs of bowel problems.

Other medicines and Cosentyx

Tell your doctor or pharmacist:

- If you are taking, have recently taken or might take any other medicines
- If you have recently had or are due to have a vaccination. You should not be given certain types of vaccines (live vaccines) while using Cosentyx

Pregnancy, breast-feeding and fertility

- It is preferable to avoid the use of Cosentyx in pregnancy. The effects of this medicine in pregnant women are not known. If you are a woman of childbearing potential, you are advised to avoid becoming pregnant and must use adequate contraception while using Cosentyx and for at least 20 weeks after the last Cosentyx dose

Talk to your doctor if you are pregnant, think you may be pregnant or are planning to have a baby.

- Talk to your doctor if you are breast-feeding or are planning to breast-feed. You and your doctor should decide if you will breast-feed or use Cosentyx. You should not do both

After using Cosentyx you should not breast-feed for at least 20 weeks after the last dose.



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How to store your medication

Do not use this medicine:

- After the expiry date which is stated on the outer box or the label on the pen after 'EXP'
- If the liquid contains easily visible particles, is cloudy or is distinctly brown

How to store this medicine:

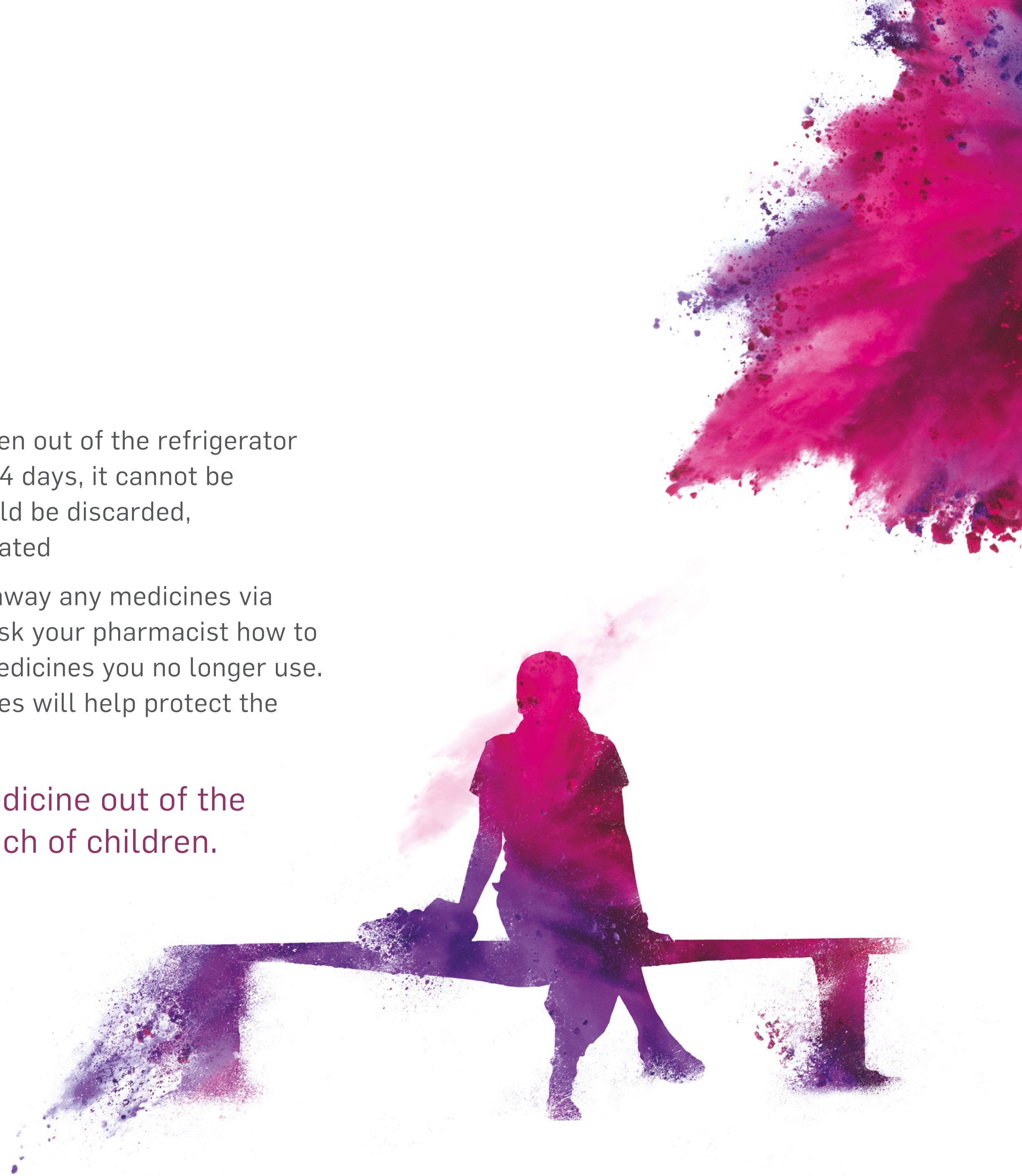
- Store the pen sealed in its box to protect from light. Store in the refrigerator between 2°C and 8°C. Do not freeze. Do not shake

This medicine is for single use only.

- If necessary, it can be left out of the refrigerator on a single occasion for up to 4 days at room temperature, not above 30°C

- Once it has been out of the refrigerator for more than 4 days, it cannot be used and should be discarded, not re-refrigerated
- Do not throw away any medicines via wastewater. Ask your pharmacist how to throw away medicines you no longer use. These measures will help protect the environment.

Keep this medicine out of the sight and reach of children.



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How to use your medication

Your doctor or dermatologist (a doctor specialised in treating skin, hair and nail conditions) will let you know how much Cosentyx you should take and for how long. Make sure you keep this guidance safe so that you can refer to it in the future.

Your medication is given via injection under your skin (known as a subcutaneous injection). You and your doctor will decide if you should inject yourself.

It is important not to try to inject yourself until you have been trained by your doctor, nurse or pharmacist. A caregiver may also give you your injection after adequate training.

For detailed instructions on the recommended dose, how to inject, and how to store your medication, see the patient information leaflet that came in the box with your medicine.

If you use more medicine than you should

Or the dose has been administered sooner than was prescribed by your doctor, inform your doctor as soon as possible.

If you forget to use this medicine

Inject the next dose as soon as you remember. Then talk to your doctor to discuss when you should inject the next dose.

Always use this medicine exactly as your doctor has told you. Check with your doctor, nurse or pharmacist if you are not sure.

If you stop using this medicine

It is not dangerous to stop using Cosentyx, however if you do, your HS symptoms may come back.

If you have any further questions on the use of this medicine, ask your doctor, pharmacist or nurse.



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Your injections

A practical guide to administering your injections

You will have been prescribed a 300 mg dose. This may be given as one injection of 300 mg or two injections of 150 mg. Check with your doctor if you are unsure.

If you are prescribed the 150 mg SensoReady® pen, please click here > to access the instructions



Scan the QR code to watch the SensoReady® pen video

If you are prescribed the 300 mg UnoReady® pen, please click here > to access the instructions



Scan the QR code to watch the UnoReady® pen video



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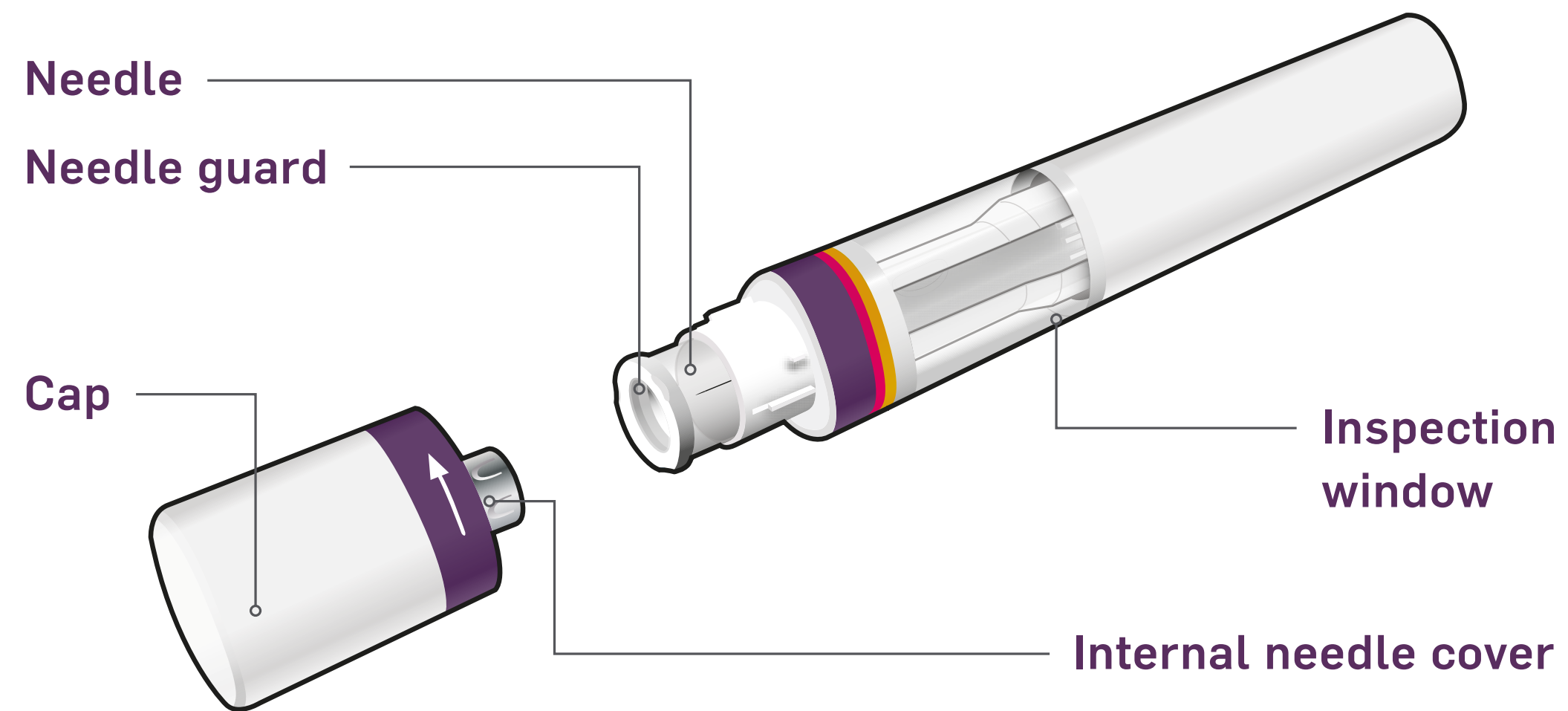
Your Cosentyx SensoReady[®] 150 mg pen



Read **ALL** the way through these instructions before injecting.

These instructions are to help you to inject correctly using the Cosentyx SensoReady[®] pen.

It is important not to try to inject yourself until you have been trained by your doctor, nurse or pharmacist.



Cosentyx SensoReady[®] pen shown with the cap removed. **Do not remove the cap until you are ready to inject.**

Store your boxed pen in a refrigerator between 2°C and 8°C and out of the reach of children.

For a more comfortable injection, take the pen out of the refrigerator 15–30 minutes before injecting to allow it to reach room temperature.

- **Do not freeze** the pen
- **Do not shake** the pen
- **Do not use the pen if it has been dropped** with the cap removed



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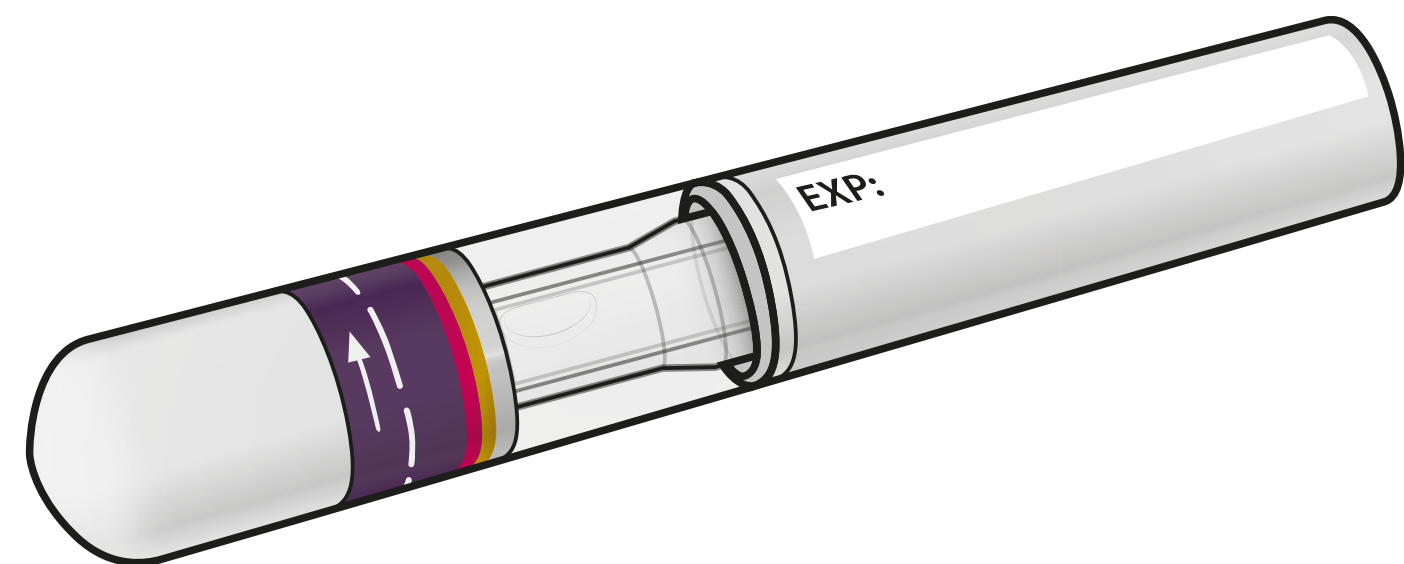
Your Cosentyx SensoReady[®] 150 mg pen

What you need for your injection:



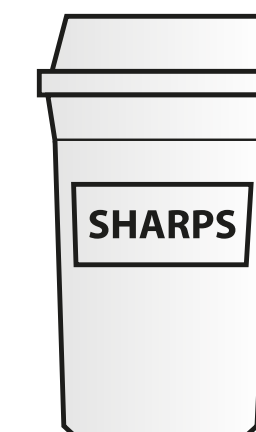
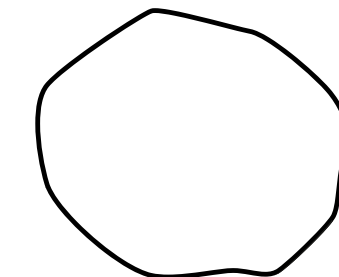
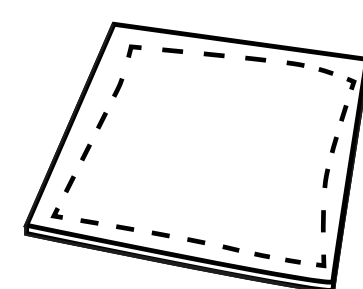
Included in the carton:

- A new and unused Cosentyx SensoReady[®] pen



Not included in the carton:

- Alcohol swab
- Cotton ball or gauze
- Sharps disposal container



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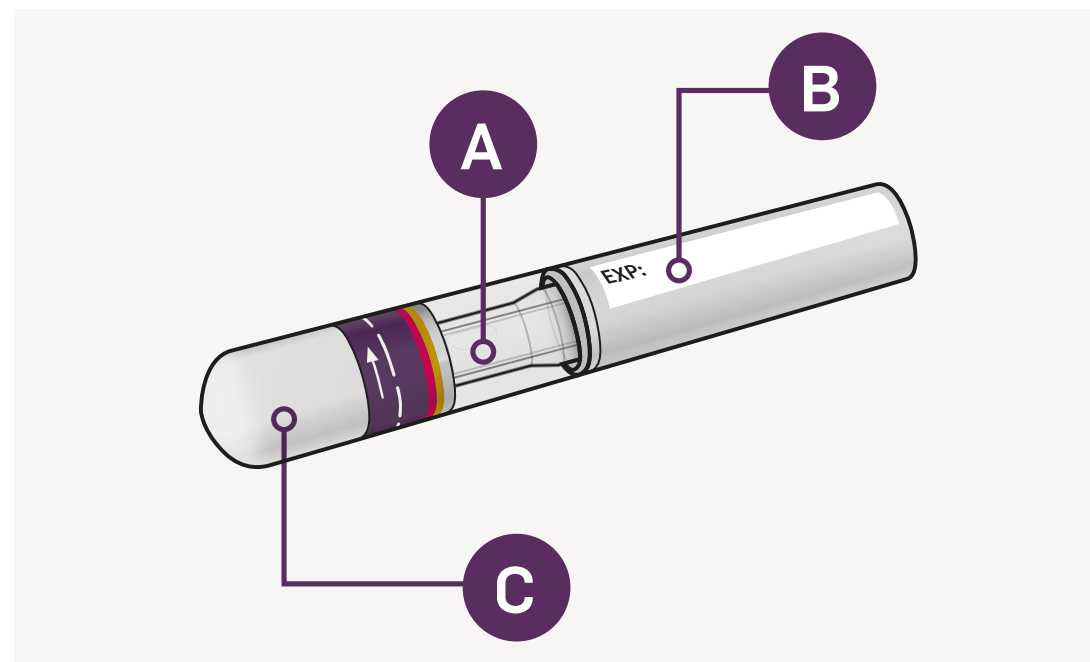
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Before your injection

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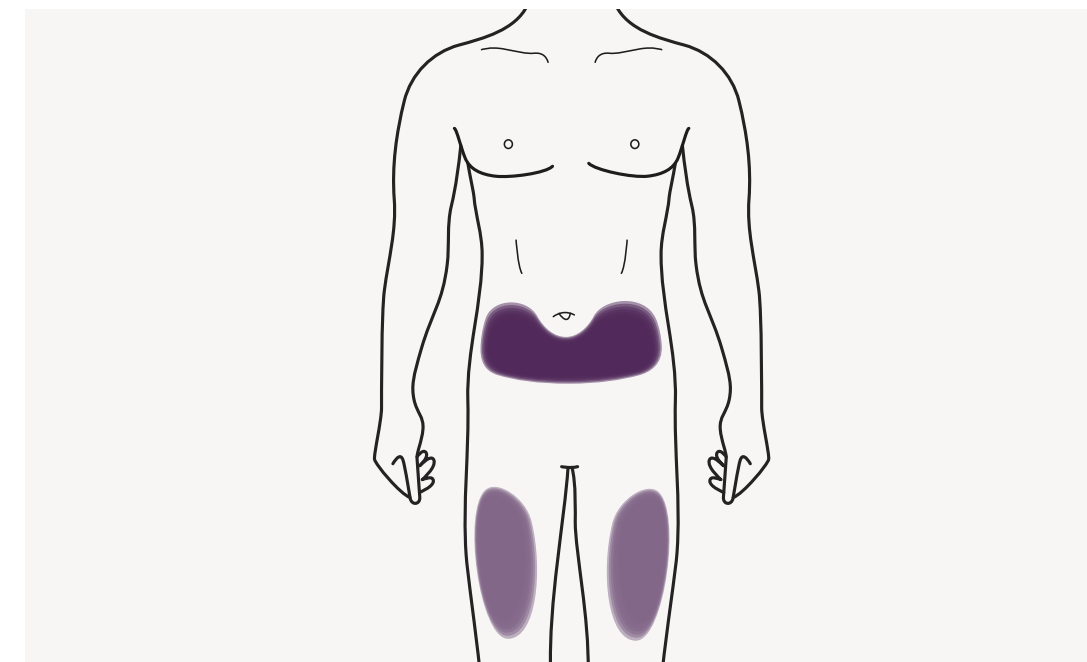
Important safety checks before you inject:

The liquid should be clear. Its colour may vary from colourless to slightly yellow.

- A. Do not use** if the liquid contains easily visible particles, is cloudy or is distinctly brown. You may see a small air bubble, which is normal
- B. Do not use** the pen if the **expiry date** has passed
- C. Do not use** if the **safety seal** has been broken

Contact your pharmacist if the pen fails any of these checks.

2a



Choose your injection site:

- The recommended site is the front of the thighs. You may also use the lower abdomen, but not the area 5 centimetres around the navel (belly button)
- Choose a different site each time you give yourself an injection
- Do not inject into areas where the skin is tender, bruised, red, scaly or hard. Avoid areas with scars or stretch marks



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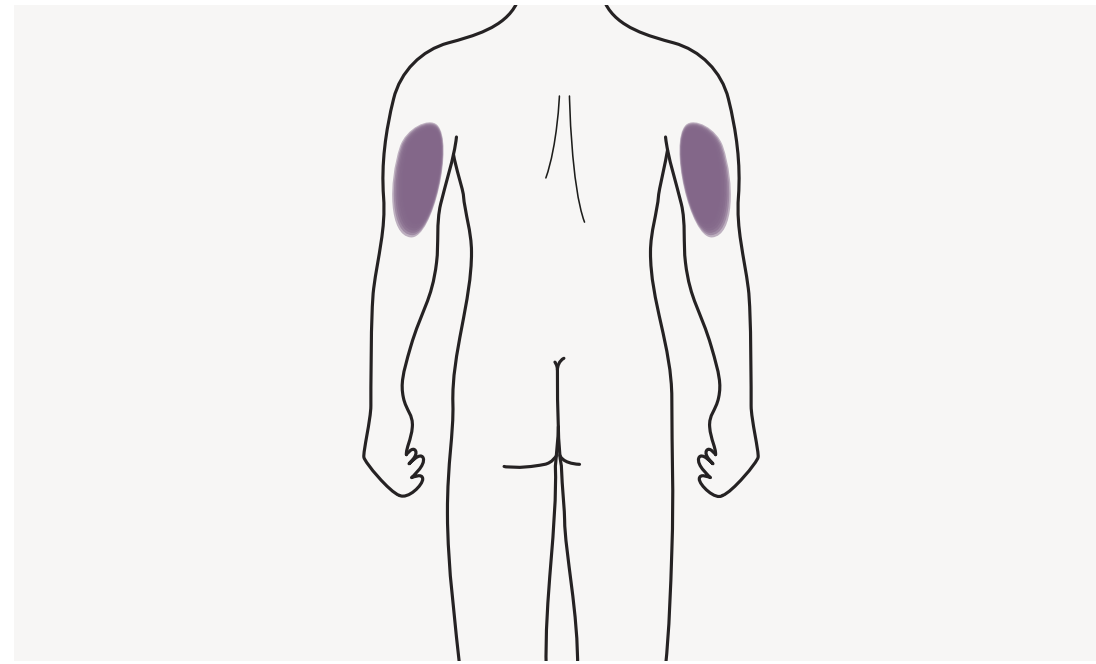
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Before your injection

2b



Caregivers and healthcare professionals only:

- If a caregiver or healthcare professional is giving you your injection, they may also inject into your outer upper arm

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Cleaning your injection site:

- Wash your hands with soap and hot water
- Using a circular motion, clean the injection site with the alcohol swab. Leave it to dry before injecting
- Do not touch the cleaned area again before injecting



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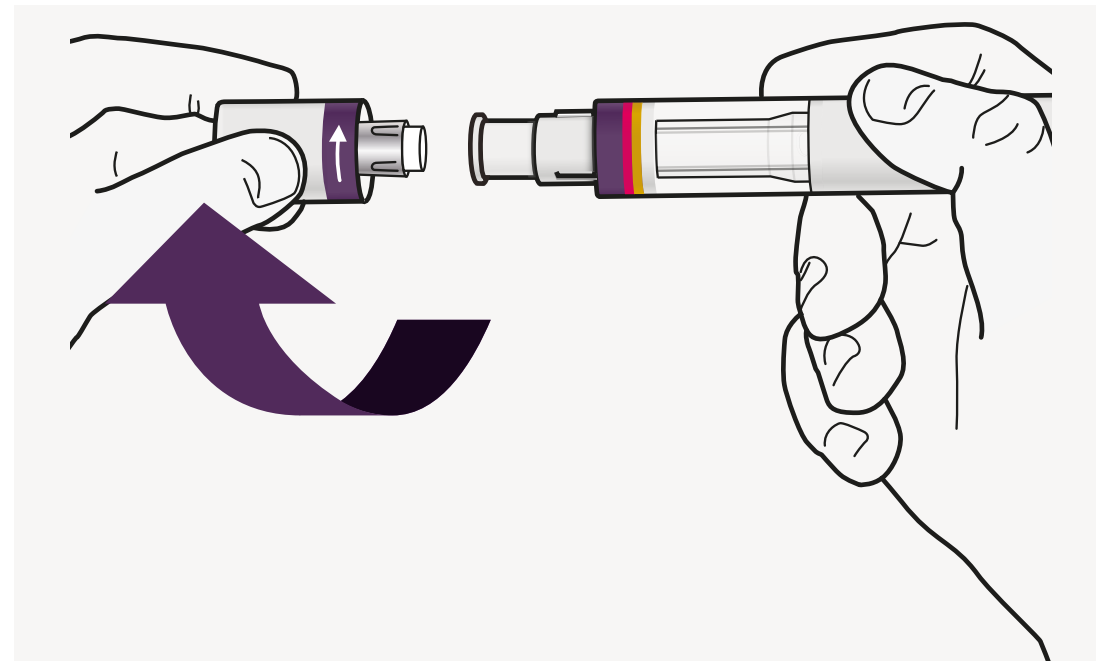
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Your injection

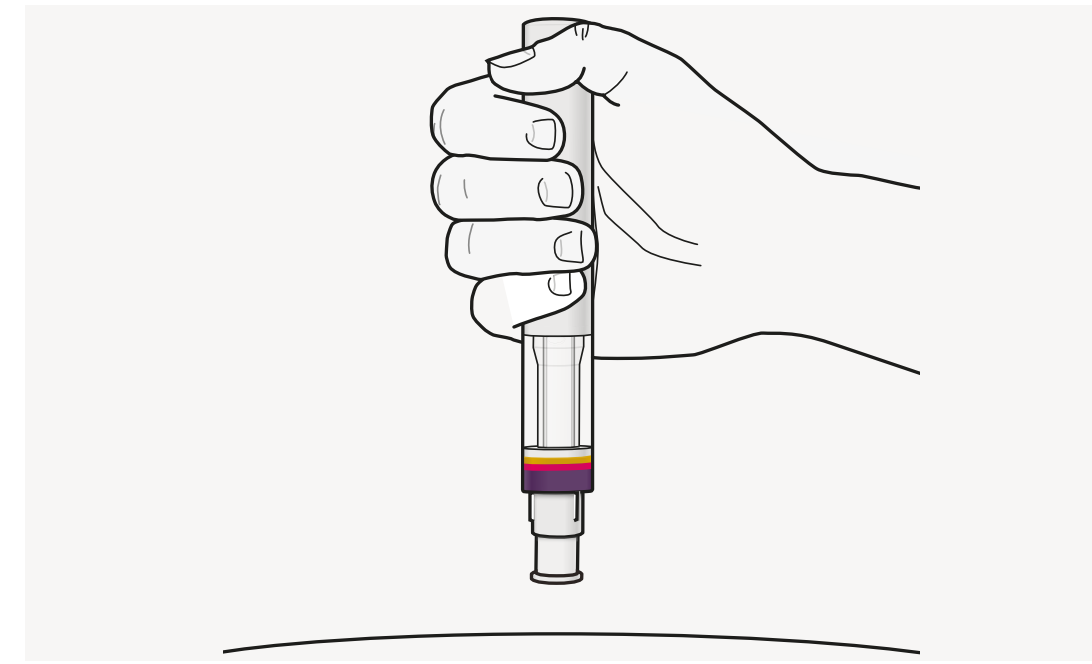
4



Removing the cap:

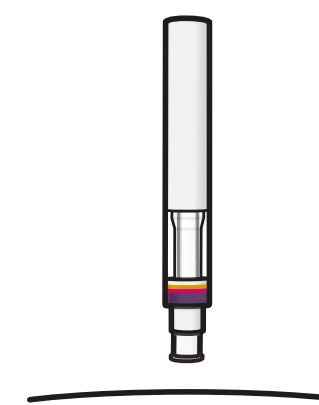
- Only remove the cap when you are ready to use the pen
- Twist off the cap in the direction of the arrows
- Once removed, throw away the cap. Do not try to re-attach the cap
- Use the pen within 5 minutes of removing the cap

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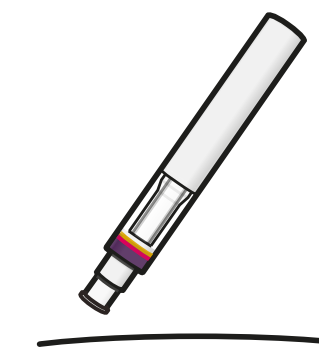


Holding your SensoReady® pen:

- Hold the pen at 90 degrees to the cleaned injection site



Correct



Incorrect



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Your injection



You must read this before injecting.

During the injection you will hear **two loud clicks.**

The **first click** indicates that the injection has started. Several seconds later a **second click** will indicate that the injection is **almost** finished.

You must keep holding the pen firmly against your skin until you see a **green indicator** fill the window and stop moving.



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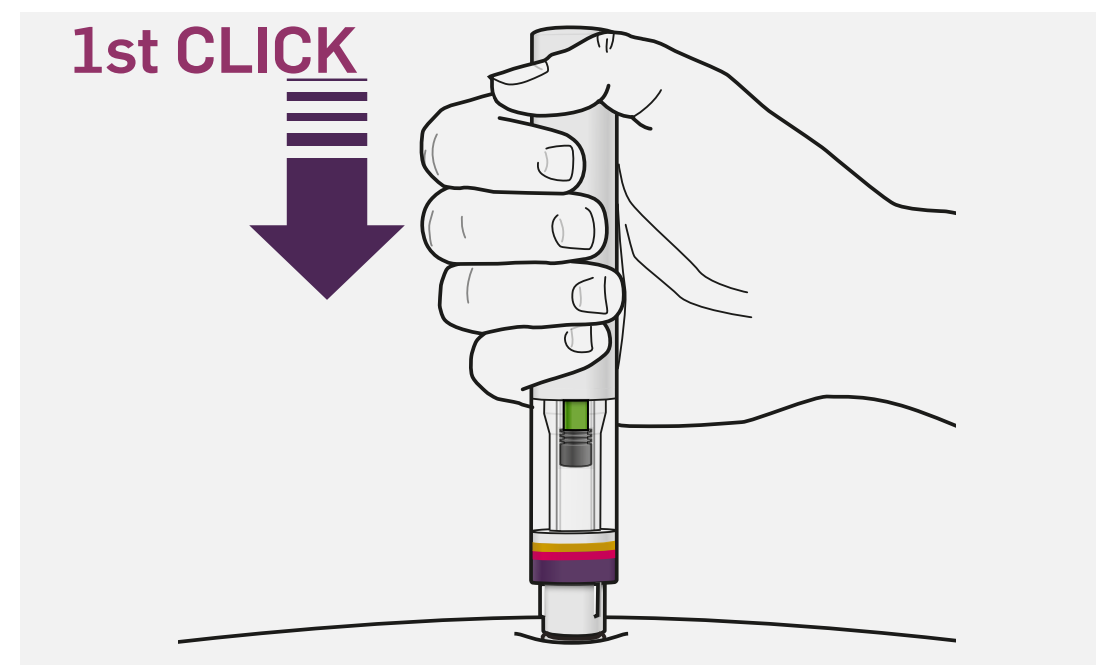
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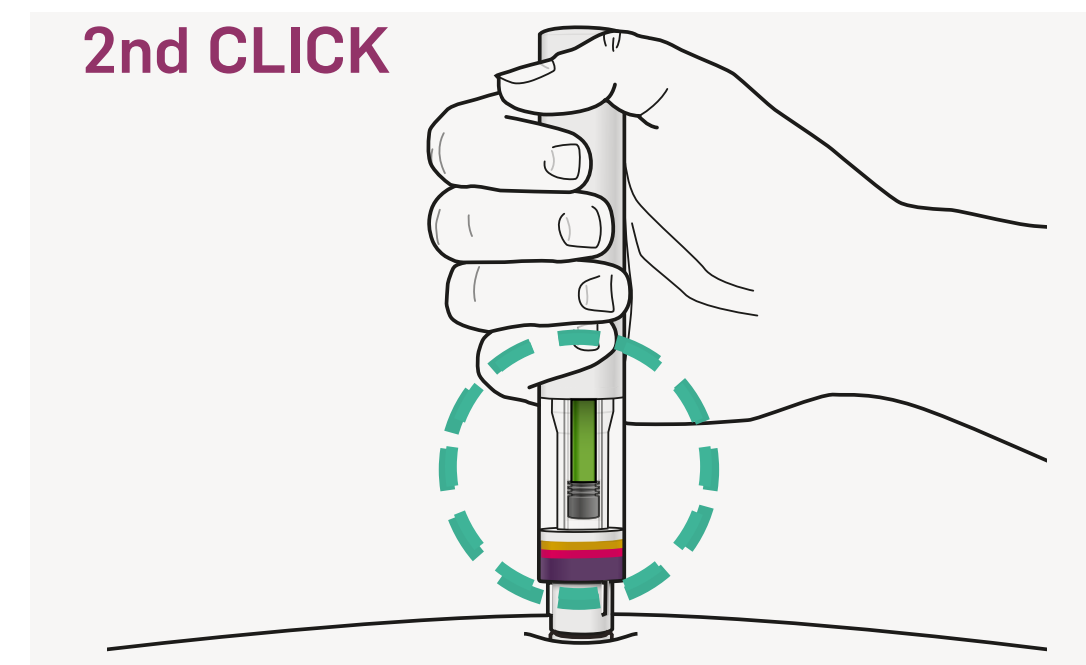
6



Starting your injection:

- Press the pen firmly against the skin to start the injection
- The **first click** indicates the injection has started
- **Keep holding** the pen firmly against your skin
- The **green indicator** with the grey tip shows the progress of the injection

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Completing your injection:

- Listen for the **second click**. This indicates the injection is **almost** complete
- Check the **green indicator** fills the window and has stopped moving
- The pen can now be removed



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After your injection

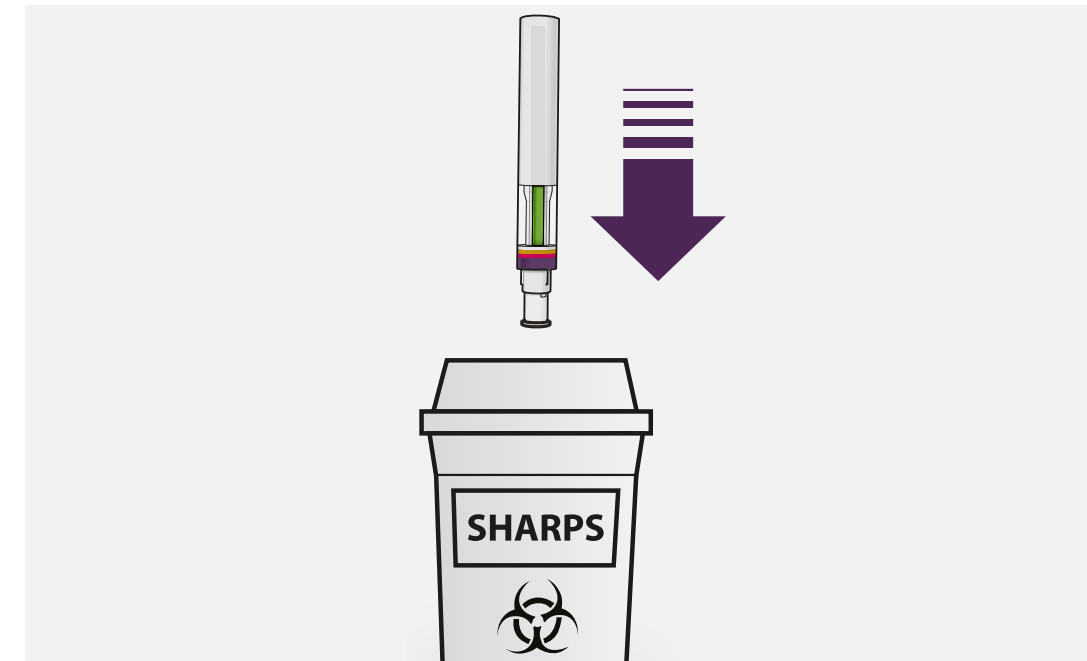
8



Check the green indicator fills the window:

- This means the medicine has been delivered. Contact your doctor if the green indicator is not visible
- There may be a small amount of blood at the injection site. You can press a cotton ball or gauze over the injection site and hold it for 10 seconds. Do not rub the injection site. You may cover the injection site with a small adhesive bandage, if needed

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Disposing of your Cosentyx SensoReady® pen:

- Dispose of the used pen in a sharps disposal container (i.e. a puncture-resistant closable container, or similar)
- Never try to reuse your pen

Remember:

- Take care to inject in an area different from your first injection



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Your Cosentyx UnoReady[®] 300 mg pen



Read **ALL** the way through these instructions before injecting.

These instructions are to help you to inject correctly using the Cosentyx UnoReady[®] pen.

It is important not to try to inject yourself until you have been trained by your doctor, nurse or pharmacist.



Cosentyx UnoReady[®] pen shown with the cap removed. **Do not remove the cap until you are ready to inject.**

Keep the Cosentyx UnoReady[®] pen in the sealed outer carton until you are ready to use it, to protect it from light.

Store your boxed pen in a refrigerator between 2°C and 8°C and out of the reach of children.

Take the pen out of the refrigerator 30–45 minutes before injecting to allow it to reach room temperature.

- **Do not freeze** the pen
- **Do not shake** the pen
- **Do not use the pen if it has been dropped** with the cap removed



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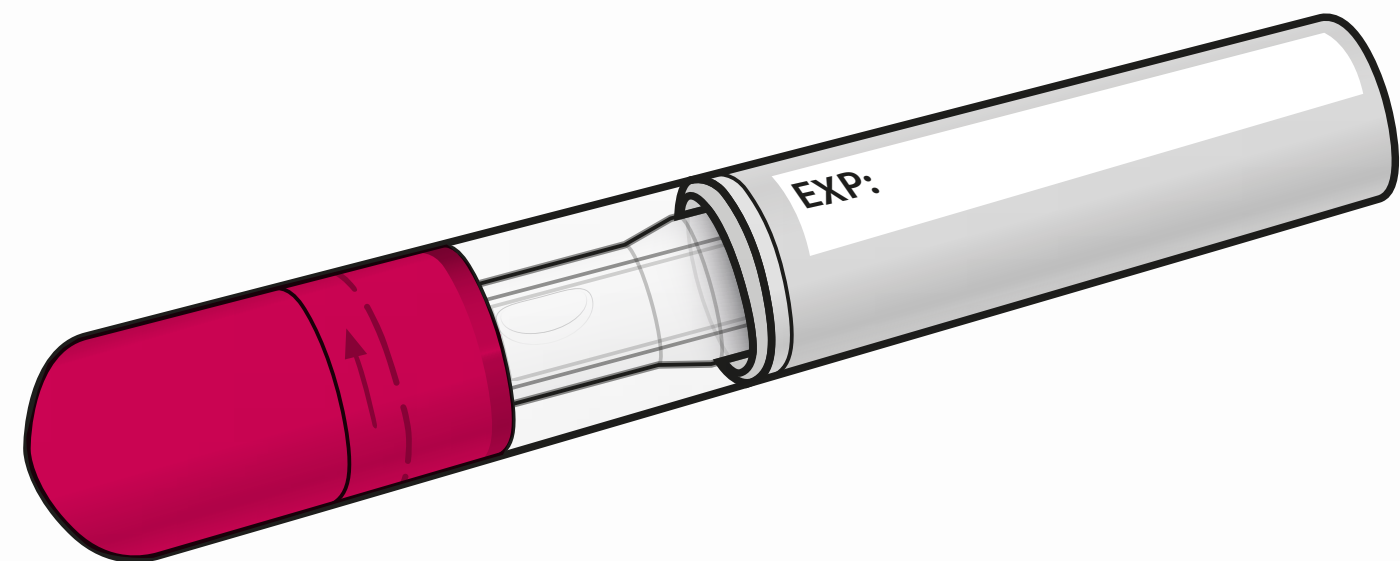
Your Cosentyx UnoReady[®] 300 mg pen

What you need for your injection:



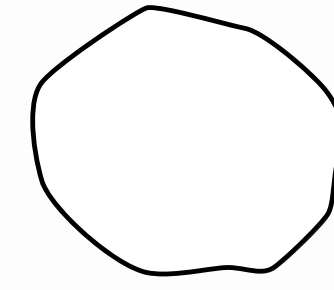
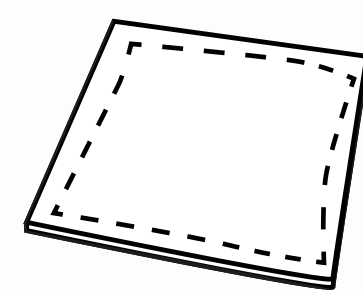
Included in the carton:

- A new and unused 300 mg dose Cosentyx UnoReady[®] 300 mg pen



Not included in the carton:

- Alcohol swab
- Cotton ball or gauze
- Sharps disposal container



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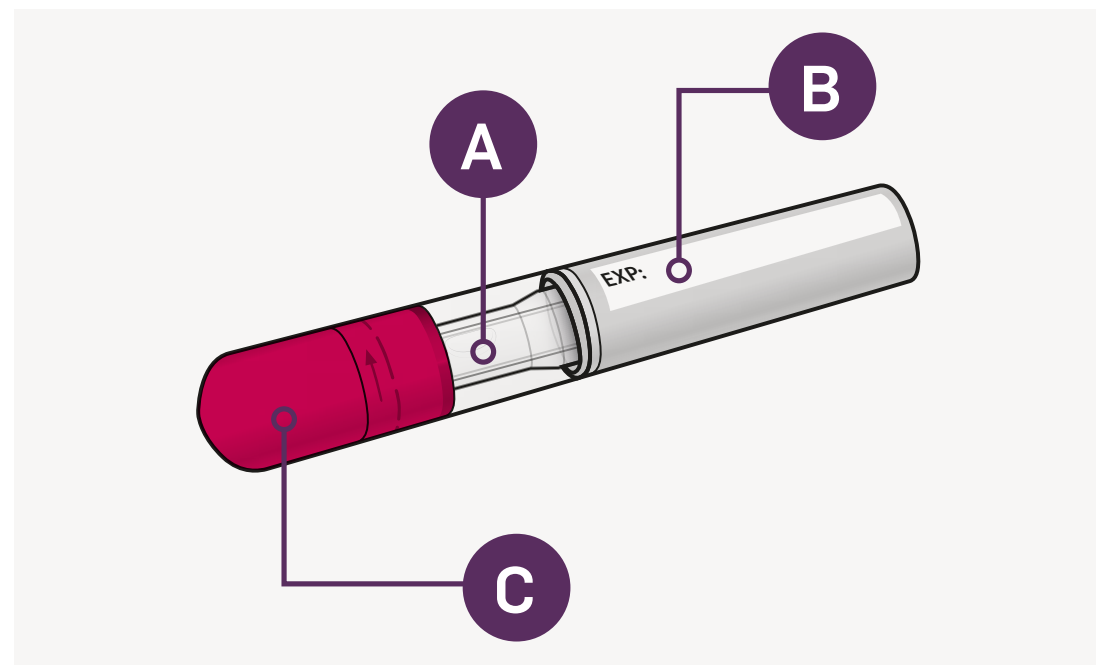
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Before your injection

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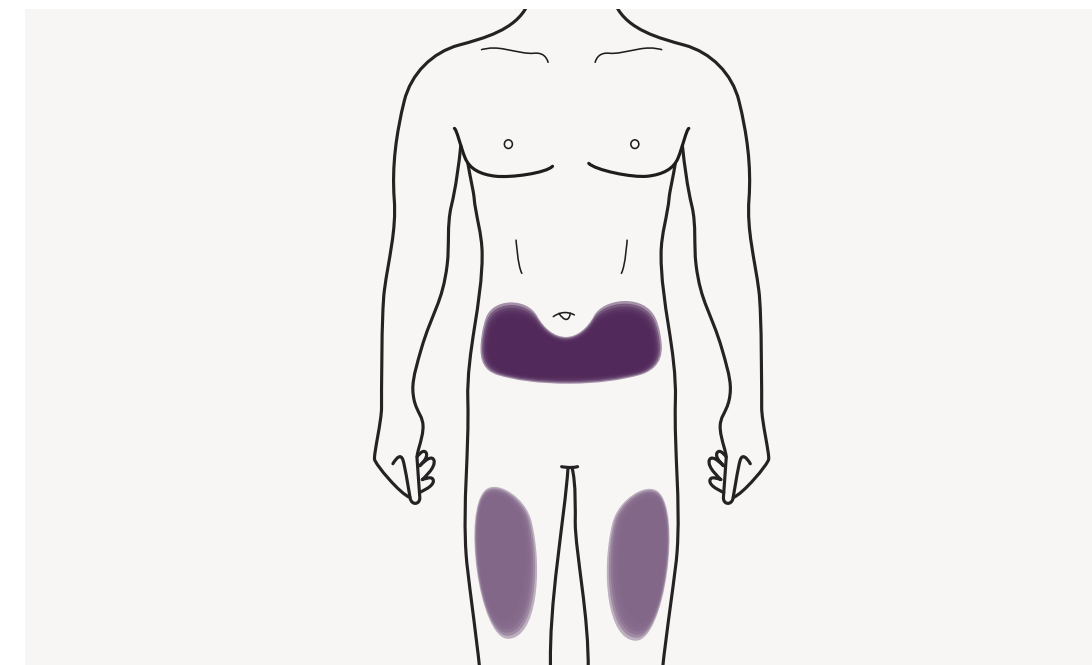


Important safety checks before you inject:

The liquid should be clear. Its colour may vary from colourless to slightly yellow.

- A. Do not use** if the liquid contains easily visible particles, is cloudy or is distinctly brown. You may see a small air bubble, which is normal
 - B. Do not use** the pen if the **expiry date** has passed
 - C. Do not use** if the **safety seal** has been broken
 - D.** Check that the pen contains the correct medicine and dose.
- Contact your pharmacist if the pen fails any of these checks.

2a



Choose your injection site:

- The recommended site is the front of the thighs. You may also use the lower abdomen, but not the area 5 centimetres around the navel (belly button)
- Choose a different site each time you give yourself an injection
- Do not inject into areas where the skin is tender, bruised, red, scaly or hard. Avoid areas with scars or stretch marks



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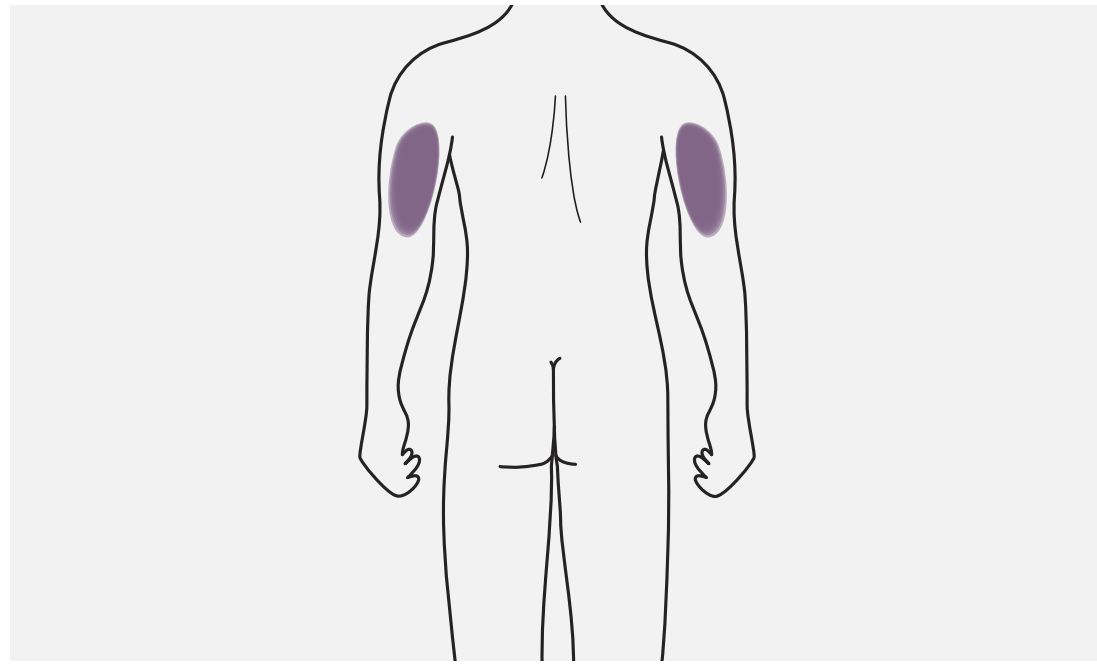
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Before your injection

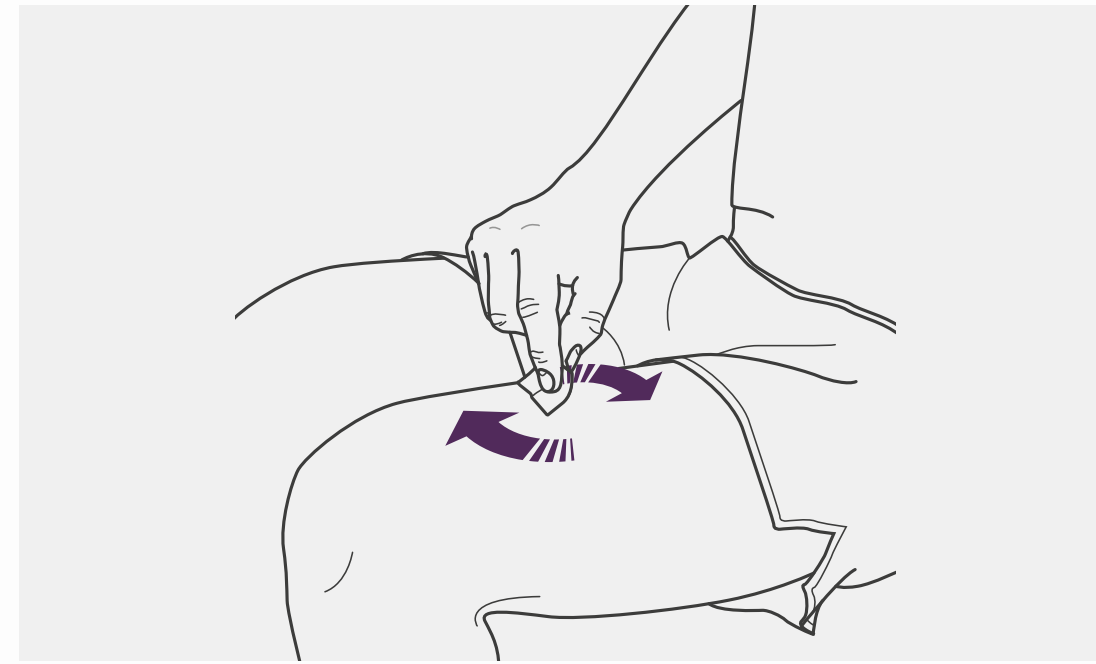
2b



Caregivers and healthcare professionals only:

- If a caregiver or healthcare professional is giving you your injection, they may also inject into your outer upper arm

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Cleaning your injection site:

- Wash your hands with soap and hot water
- Using a circular motion, clean the injection site with the alcohol swab. Leave it to dry before injecting
- Do not touch the cleaned area again before injecting



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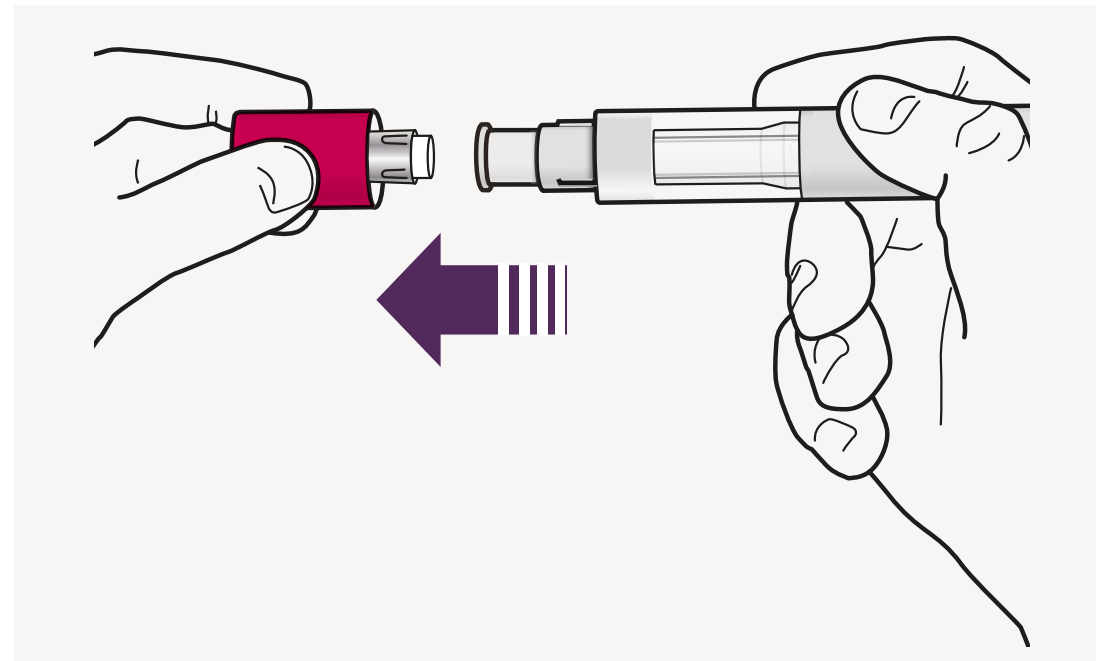
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Your injection

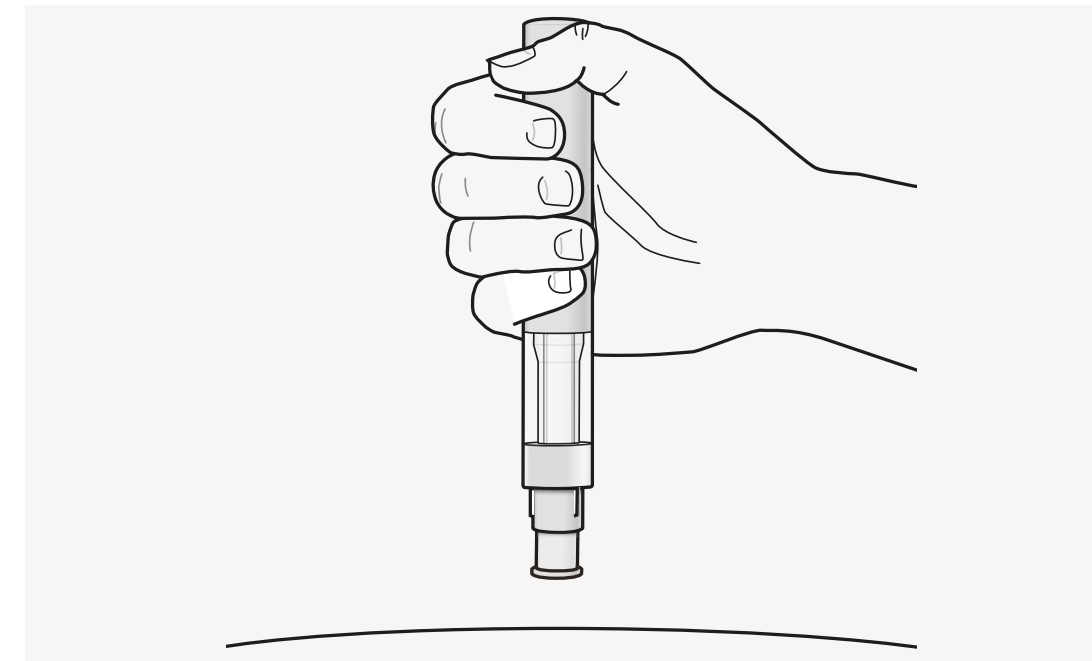
4



Removing the cap:

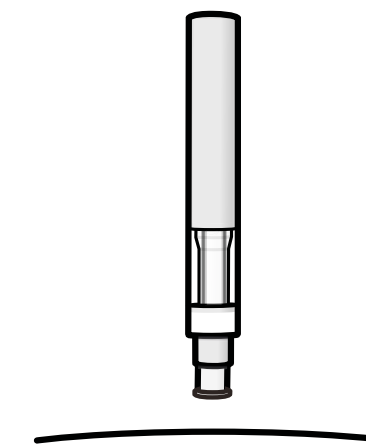
- Only remove the cap when you are ready to use the pen
- Pull off the cap in the direction of the arrow
- Once removed, throw away the cap. Do not try to re-attach the cap
- Use the pen within 5 minutes of removing the cap

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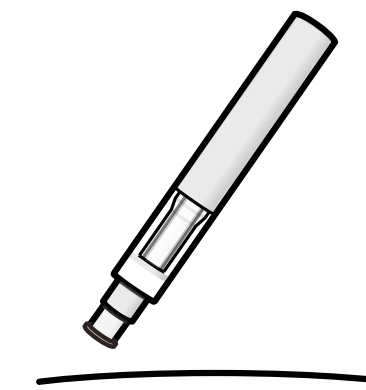


Holding your UnoReady® pen:

- Hold the pen at 90 degrees to the cleaned injection site



Correct



Incorrect



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Your injection



You must read this before injecting.

During the injection you will hear **two clicks**.

The **first click** indicates that the injection has started. Several seconds later a **second click** will indicate that the injection is **almost** finished.

You must keep holding the pen firmly against your skin until you see a **green indicator with a grey tip** fill the window and stop moving.



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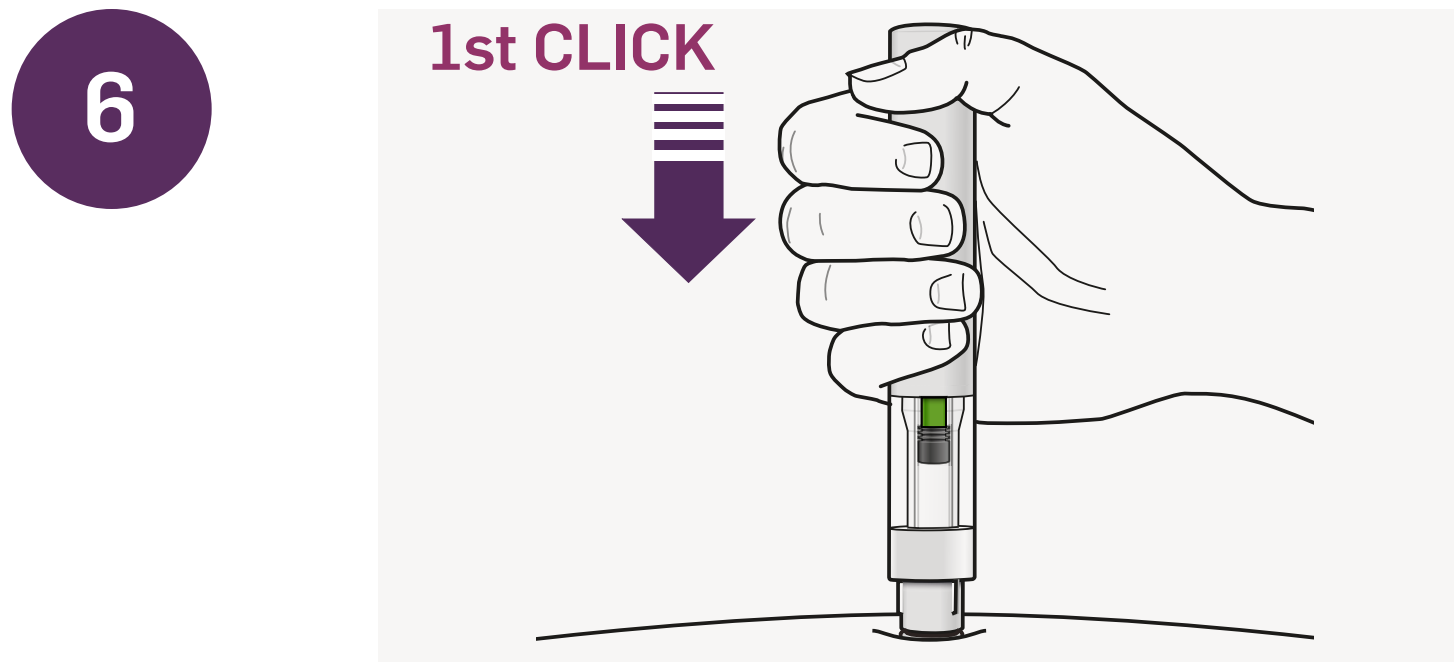


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Your injection

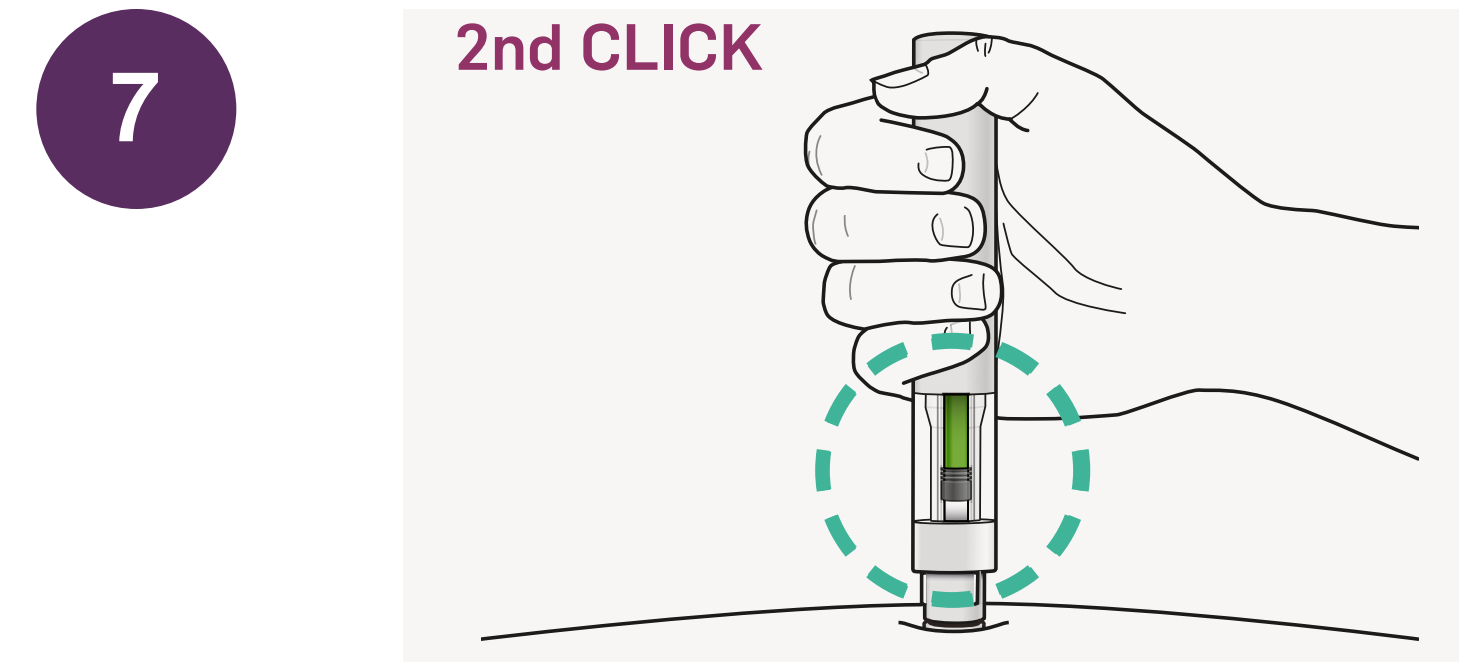


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Starting your injection:

- Press the pen firmly against the skin to start the injection
- The **first click** indicates the injection has started
- **Keep holding** the pen firmly against your skin
- The **green indicator** with the grey tip shows the progress of the injection



Completing your injection:

- Listen for the **second click**. This indicates the injection is **almost** complete
- Check the **green indicator** with the grey tip fills the window and has stopped moving
- The pen can now be removed



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After your injection

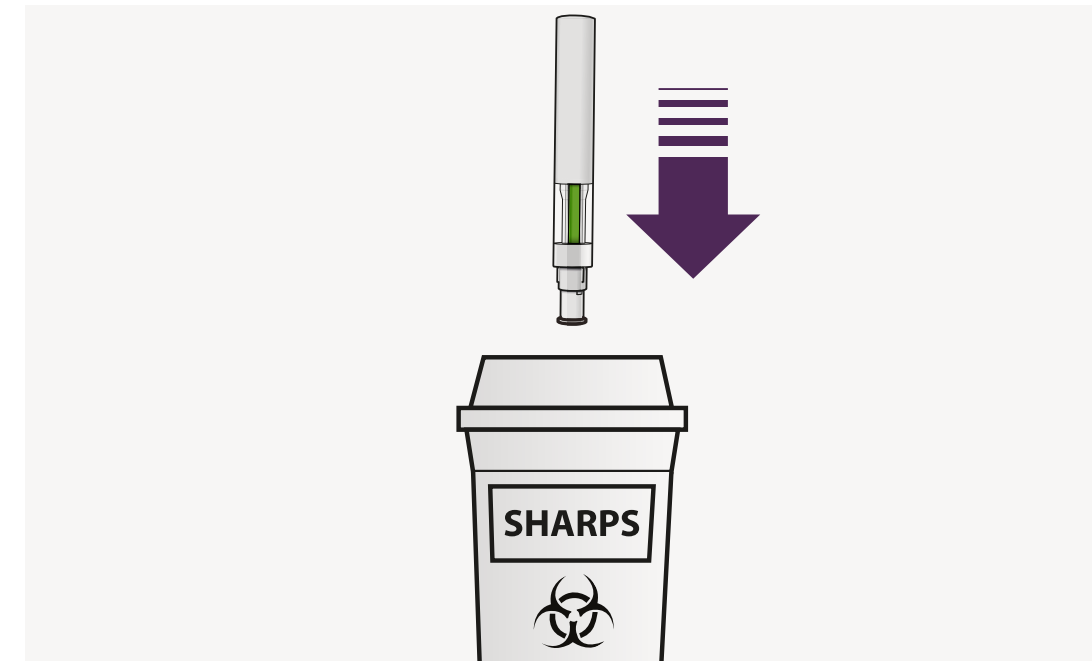
8



Check the green indicator fills the window:

- This means the medicine has been delivered. Contact your doctor if the green indicator is not visible
- There may be a small amount of blood at the injection site. You can press a cotton ball or gauze over the injection site and hold it for 10 seconds. Do not rub the injection site. You may cover the injection site with a small adhesive bandage, if needed

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Disposing of your UnoReady® pen:

- Dispose of the used pen in a sharps disposal container (i.e. a puncture-resistant closable container, or similar)
- Never try to reuse your pen



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Your wellbeing

Tips to help with reducing the impact of your condition on everyday life

Living positively with hidradenitis suppurativa

By now you probably have a good understanding of how HS affects you on a daily basis – not just in terms of your skin but also the way you feel. Starting a different treatment for your HS may be a good time to look at other parts of your lifestyle to see what you can do to reduce the impact HS has on your life.

Treatment of HS requires patience and time. Adopting a healthy lifestyle can help you manage your condition and improve your overall wellbeing.

This chapter contains hints and tips that may reduce the impact of HS on your life.



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Managing emotions

Feeling down?

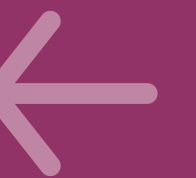
If you feel down for more than a short time, this could be depression. Around 40% of people with HS suffer from depression.

- Talk to your doctor if you are feeling down or depressed. They may suggest things that can help you start to feel better

- If your HS contributes to your depression, ask your doctor about support groups



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Diet and lifestyle

Diet

Patients with HS are more likely to have diabetes, high cholesterol, obesity, and high blood pressure, so it is important to aim for a healthy diet and lifestyle to minimise your risk of these conditions.

Try keeping a food diary for a couple of weeks, to see if you can identify where you could make healthier choices.

- Think about the types of fat that you eat and cook with – cut back on saturated fats (such as butter and vegetable oil), and instead use olive oil and use low-fat dairy products
- Aim to eat more vegetables, fruit and wholegrain cereals

- Eat oily fish at least twice a week
- Choose lean meats and poultry without skin
- Avoid pre-packaged convenience food and fast food, which can often contain hidden calories and high levels of fat and salt
- Keep an eye on your portion size

Smoking

There is increasing evidence that smoking can make HS worse. If you smoke, maybe now is the time to talk to your doctor or pharmacist for advice on quitting for good.



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Tips for day-to-day life with hidradenitis suppurativa

Exercise

Exercise is not only good for fitness and strength, it's also a great stress-buster.

Regular exercise can also help you maintain a healthy weight and may reduce your risk of heart disease and diabetes.

There are lots of different types of exercise to choose from. You could try:

- Walking or hiking
 - Wearing loose clothing may help to minimise friction on your skin
- Yoga or tai chi for something low impact and relaxing

Relationships

- Your decision to discuss your condition is down to you and what you feel comfortable with
- It can be really helpful to let your family, friends and/or partner know how you feel – especially if HS is getting you down. They may be able to offer you support
- If you are just starting a relationship, consider raising the subject of your condition with your partner sooner rather than later. This may help you feel more in control of the situation

If it's been a while since you've done any exercise, speak to your doctor or nurse before starting, then begin slowly and build up over time.



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Tips for day-to-day life with hidradenitis suppurativa

Work and HS

If you have visible lesions, it's natural that potential employers or your colleagues will notice them, so you may want to consider:

- Briefly explaining that you have HS at the outset of a new job or meeting with new people
- Educating your employers and colleagues about HS
- Talk to your employer about specific challenges (such as difficulty sitting for long periods)
- Your decision to discuss your HS with potential employers or colleagues is down to you and what you feel comfortable with. Your success in job interviews or career progression should be based on your abilities and skills, not your HS.

Taking your treatment as prescribed to get the most benefit

- Programme dose reminders into your phone, mark your doses on your calendar, or try leaving notes and reminders around the house where you will see them
- If you are going away, plan ahead. If you think you will need additional doses, speak to your doctor, nurse or pharmacist in advance so they have plenty of time to order what you need

See the **Your travel plans** chapter for tips about taking your treatment with you when you travel.



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Your travel plans

A guide to managing your condition
and treatment away from home

Travelling with your medication

Everyone likes the freedom of travel, but when you have a medicine to think about, it can take a bit of forward planning.

That's why this chapter includes tips on how to travel with your medicine and ensure it's stored properly while you're away. There is also a checklist of things to do before you go.

By planning ahead and ensuring you have everything you need, you can make sure your time away goes as smoothly as possible.

Quick facts

- While travelling, your medication should be kept cool – between 2°C and 8°C
- You should not freeze your medicine or use freezer packs
- If necessary, it can be left out of the refrigerator on a single occasion for up to 4 days at room temperature, not above 30°C
- Once it has been out of the refrigerator for more than 4 days, it cannot be used and should be discarded, not re-refrigerated



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Checklist

A few weeks before you travel

Request a copy of your prescription to confirm that you are travelling with the medication that has been prescribed for you

Talk to your doctor to arrange to take enough medicine with you for your trip

Check with your pharmacist that you have everything that you need to administer your treatment (such as cotton balls, alcohol swabs, etc.)

If you are going on a long-haul flight, speak with your airline to let them know you that you will need to store your medicine in the fridge on the plane (not the freezer) to make sure it is kept at the right temperature

Calculate when your next dose is due. Your medication can be left out of the refrigerator on a single occasion for up to 4 days at room temperature, not above 30°C. If your dose is due within 4 days of travel, it does not need to be refrigerated or carried in a cool pack unless temperatures may go above 30°C

Ring your place of accommodation to check that there is a refrigerator available for you to use

A couple of days before you travel

Put cotton balls or gauze, and alcohol swabs into your travel pack

– You will need these in addition to your Cosentyx UnoReady® or SensoReady® pens

Speak with your doctor or pharmacist about how to transport your medicine

Before you leave home

Make sure you have your letter from your doctor or a copy of your prescription

If you are flying, pack your medicine in your hand luggage as it may freeze in the luggage hold

At the airport

Let airport security know you are carrying injectable medication before they scan your bag

Keep your prescription and letter from your doctor handy



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Your sources of support

A guide to where you can go for more information about your treatment and living with HS

Staying on top of your condition can be easier when you know about the resources that are available to help you. Finding support from others who understand how you feel and what you are going through can also help you cope if you are finding things difficult. This chapter provides information on a range of groups and initiatives set-up to help manage life with HS and its treatment.

Support group benefits

- Increase your self-confidence and reduce feelings of isolation
- Chance to talk with and learn from other people with first-hand experience of living with HS
- Opportunity to help others by sharing your experiences



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Support for you

Support groups

Currently, there are not many support groups in the UK, particularly at a national level. If you don't know of a support group in your area, ask your doctor or nurse, or check the notice boards in health centres and pharmacies.

If you find there isn't a support group locally, think about starting one yourself – even just an informal meeting at a coffee shop each month.

Support with treatment

For medical advice or side effect questions

Talk to your doctor, pharmacist or nurse. This includes queries on any possible side effects not listed in the patient information leaflet that came in the Cosentyx box.

For prescription questions

Contact your doctor or pharmacist.

For Homecare service and delivery questions

Call the **Your Homecare support line** or email **bionical.spa@nhs.net**.

Please see the leaflet provided with your patient pack for details.



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Frequently asked questions



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Frequently asked questions

How do I take my medicine?

Cosentyx is given via an injection under your skin (subcutaneous injection). Injections are given using Cosentyx UnoReady® pens.

How long does treatment last?

Cosentyx is a long-term treatment. You should continue using it even if your symptoms improve. Your doctor will regularly monitor your condition to check that the treatment is having the desired effect.

How long can I store my medicine?

Do not use the Cosentyx UnoReady® pens after the expiry date which is on the outer box or the label on the pens after 'EXP'.

What should I do if I notice that the liquid in my Cosentyx UnoReady® pen is cloudy?

Do not use your Cosentyx UnoReady® pen if the liquid contains easily visible particles, is cloudy or is distinctly brown.

What should I do if I administer a dose before my scheduled injection date?

If you have received more medicine than you should or the dose has been administered sooner than according to your doctor's prescription, inform your doctor as soon as possible.

What should I do if the Cosentyx UnoReady® pen doesn't work?

If you think your pen is not working correctly or are unsure whether you have correctly injected using the pen, please contact your doctor or pharmacist.

What should I do with Cosentyx UnoReady® pens after my injection?

- Dispose of the used pen in a sharps disposal container (i.e. a puncture-resistant closable container, or similar)
- Never try to reuse your pen
- Do not throw away any medicines via waste water. Ask your pharmacist how to throw away medicines you no longer use. These measures will help protect the environment



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Frequently asked questions

Can I take other medications while being treated with Cosentyx?

Tell your doctor or pharmacist:

- if you are taking, have recently taken or might take any other medicines
- if you have recently had or are due to have a vaccination. You should not be given certain type of vaccines (live vaccines) while using this medicine

What should I do if I forget an injection?

If you have forgotten to inject a dose, inject the next dose as soon as you remember. Then talk to your doctor to discuss when you should inject the next dose.

What should I do if I stop using my medicine?

It is not dangerous to stop using your medication. If you have any further questions on the use of this medicine, ask your doctor, pharmacist or nurse.

What should I do if there is a spot of blood at the injection site?

There may be a small amount of blood at the injection site. You can press a cotton ball or gauze over the injection site and hold it for 10 seconds. Do not rub the injection site. You may cover the injection site with a small adhesive bandage, if needed.

Is HS inherited? Will my children have HS?

Around 40% of HS cases are passed on from family members, but the way that it is inherited is not yet fully understood. There are lots of different genes involved. However, even if your children inherit a combination of genes that predisposes them to HS, it does not mean that HS will definitely develop.

How is HS diagnosed?

In most cases, doctors can diagnose HS by visually examining the affected areas of skin.



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Frequently asked questions

How do I know how severe my HS is?

There are lots of different tools available to help your doctor determine how severe your HS is. These include Hurley staging, the International HS severity score system (IHS4) and the dermatology life quality index (DLQI).

Is there a cure for HS?

There is currently no cure for HS, but treatment to control the signs and symptoms is available. However, remember that what works for one person may not work for another, so it is important to discuss treatment management with your doctor.

Is all HS alike?

The appearance of HS can vary from person to person and over time. Patients may have different types of lesions (comedones, nodules, abscesses, tunnels, scarring etc.) to different degrees compared to other HS patients.

Does HS affect all parts of the body?

HS can occur in almost any skin area, but is most common in the area under the breasts, the armpits, inner thighs, groin and buttocks.

At what age does HS usually occur?

HS tends to appear between the 20s and 30s, and it rarely appears before puberty.

If you have any other questions about your medication, please speak to your doctor, nurse or pharmacist.

How should I look after my skin if I have HS?

One of the most important steps you can take if you have HS is to take any treatment as prescribed by your doctor and follow instructions for the correct use of your treatment.

Is HS contagious?

HS is not contagious – you cannot catch HS from other people, and other people cannot catch HS from you.



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Reporting of side effects

If you get side effects with any medication you are taking, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the information leaflet that comes in the pack. You can report side effects via the Yellow Card Scheme at yellowcard.mhra.gov.uk. By reporting side effects you can help provide more information on the safety of your medication.



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