



Arginine Vasopressin Deficiency (AVP-D) formerly known as Cranial Diabetes Insipidus (DI)

Advice when you are unwell

Information for patients
Medical



This leaflet will give you information of how to manage your Arginine vasopressin deficiency (AVP-D) when you are unwell. Arginine vasopressin deficiency (AVP-D) can be life threatening. It can cause your sodium level to become high or low if not managed properly.

You should consider wearing an 'emergency bracelet' that tells people that you take Desmopressin (and any other important medications like Hydrocortisone and Levothyroxine) and/or put an alert on your phone. This is in case you are unwell and unable to tell hospital staff yourself. You should also let family and friends know about your Desmopressin so that they can speak with hospital staff, if you are not able to do so.

It is very important that if you are contacting out of hours services such as NHS 24 or an emergency GP you tell them you have arginine vasopressin deficiency (AVP-D) and you are on Desmopressin (DDAVP).

In the vast majority of illnesses you should continue your desmopressin as normal and don't increase (take more of) your normal dose. In the following situations you should consider:

Illness	Action	Get medical assistance
Heavy cold, blocked nose or sinusitis.	Take your desmopressin as normal. If you are using a desmopressin nasal spray switch to a tablet or a melt while you are ill to make sure you receive the full dose.	Yes – if unable to take desmopressin and unable to maintain fluid intake.

Illness	Action	Get medical assistance
	<p>Equivalent doses:</p> <ul style="list-style-type: none"> ❖ 1 nasal spray desmopressin 10mcg ❖ desmopressin tablets 100mcg ❖ DDAVP melt (60mcg) <p>Maintain fluid intake.</p>	
Vomiting or diarrhoea (more than once).	<p>Take desmopressin as normal.</p> <p>Drink plenty of water - lots of small sips are better.</p>	<p>Yes – you need to make sure your AVP is stable. You will need urgent medical attention if the vomiting or diarrhoea is severe or you are unable to retain your desmopressin.</p>
Fever or unusually hot temperature (i.e. on Holiday)	<p>Take desmopressin as normal.</p> <p>Maintain fluid intake, likely to need extra fluid to cover loss.</p>	<p>Yes – if your urine output remains low.</p>

Illness	Action	Get medical assistance
<p>You have taken too much DDAVP (more than your normal dose).</p>	<p>Miss your next desmopressin dose or take it at a later time</p> <ul style="list-style-type: none"> ❖ Limit how much you are drinking until the amount of urine you are passing is back to normal for you. ❖ Allow yourself to get thirsty and pass excess urine before taking your next dose. 	<p>Yes if your urine output remains low.</p>
<p>Headache, irritable, increasing tiredness, nausea, loss of appetite, muscle cramps, confusion, reducing level of consciousness.</p>	<p>Attend A&E.</p>	<p>Yes – attend A&E urgently. If your symptoms are severe you may need to call an ambulance on 999.</p>

Illness	Action	Get medical assistance
Convulsions or seizures.	Dial 999.	Yes – you need urgent medical care.
You have missed or cannot take your desmopressin.	Drink until you're not thirsty any more.	If you have no access to water get medical advice.
If you have taken your desmopressin as normal but have then had a lot to drink.	<p>Miss your next dose of desmopressin or take it at a later time.</p> <p>Limit fluid intake until the amount of urine you are passing is back to normal for you.</p> <p>Allow yourself to get thirsty and pass excess urine before taking your next dose.</p>	Yes – if your urine output remains low.

If you are concerned about your medical condition get medical advice.

WHAT HAPPENS IF I AM ADMITTED TO HOSPITAL?

You should let the healthcare team looking after you know that you need desmopressin as a life-preserving replacement therapy for your Arginine Vasopressin Deficiency (AVP-D).

Make sure the hospital staff understand that you must receive your Desmopressin. Sometimes doctors and nurses might think that Desmopressin is not important because it can be given as a nasal spray.

Ask the hospital staff to discuss your details with the endocrine team in that hospital.

FURTHER INFORMATION

If you need information on Arginine Vasopressin Deficiency (AVP-D) please go to www.pituitary.org.uk or <https://www.pituitary.org.uk/information/avp-deficiency-di/>

If you have any questions please contact the department on:

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ALERTS

Your GP should add an alert on your Key Information Summary (KIS) that you have Arginine Vasopressin Deficiency and you are on Desmopressin. Your endocrine team should make sure there is an alert on the local hospital system.

GUIDANCE TO HEALTHCARE PROFESSIONALS – ARGININE VASOPRESSIN DEFICIENCY PATIENT

As A&E, ward staff or a general health care professional, you may care for a patient with the condition Arginine Vasopressin Deficiency (AVP-D). It is important that you know what this condition is and also that you understand the importance of the medication which Arginine Vasopressin Deficiency (AVP-D) patients take to manage their condition.

Arginine Vasopressin Deficiency (AVP-D) is not linked in any way to diabetes mellitus.

Arginine Vasopressin Deficiency (AVP-D) is a disorder in which the kidneys are unable to retain water, caused by the lack of a water-retaining (anti-diuretic) hormone produced by the pituitary gland. This results in the production of large amounts of urine and in turn, a greatly increased thirst.

The condition requires medication to manage it effectively. Without such medication (DDAVP), the condition will cause patients to become dangerously dehydrated and in extreme situations this can become fatal.

The healthcare team seeing the patient should get advice from an endocrinologist if required.

HOW WE KEEP YOUR HEALTH INFORMATION SECURE

NHS Lanarkshire take care to make sure that only people who are allowed to can access your personal information. Our staff have a legal duty to keep information about your health safe, secure and private.

If you want to learn more about how we do this, you can visit our website at <https://www.nhslanarkshire.scot.nhs.uk/data-protection-notice> You can also ask a member of staff for a copy of our Data Protection Notice.

NHS Lanarkshire - for local services and the latest health news visit www.nhslanarkshire.scot.nhs.uk

NHS Lanarkshire General
Enquiry Line: 0300 30 30 243

NHS inform - The national health information service for Scotland.
www.nhsinform.co.uk
Tel No: 0800 22 44 88

For NHS staff only -

For advice on how to get a leaflet translated for your patients, please contact: patientinformation@lanarkshire.scot.nhs.uk

For patient letters, records etc. please email: translation.services@lanarkshire.scot.nhs.uk



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