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**Sick day rules advice for AVP-D (diabetes insipidus) patients**

**The healthcare team seeing the patient should seek advice from an endocrinologist experienced in AVP-D (DI)**

**When should I seek medical attention?**

You should seek medical attention if any of the following happen:

**1)** **You have missed or cannot take your desmopressin and have little or no access to fluids**; this means you will continue to lose water as you will not be able to control your urine output, BUT you cannot replace this as you have little or no intake. This can very quickly lead to your becoming dehydrated with an increase in your blood sodium level. This would be known as hypernatraemia.

**Hypernatraemia (high sodium)**

**A high sodium is very uncommon unless the body is severely lacking in water. If this is not recognised and treated it can be life-threatening as it can cause problems with the brain and central nervous system.**

**For a patient with AVP-D (DI), hypernatraemia develops when desmopressin is not taken / given and intake of fluid is low or nil.**

It can also develop if you have an episode of gastroenteritis or repeated vomiting, due to increased fluid loss caused by vomiting and/or diarrhoea. Correcting a too high sodium level should be done carefully to prevent too sudden a drop.

**What symptoms may I have?**

Symptoms of a high sodium can include headaches, fatigue or tiredness, irritability, dry mouth and lips, nausea and reduced appetite, cramps, muscle spasms and if left untreated or not recognised convulsions or seizures may occur.

**Seeking help:**

* **Attend your GP without delay if early symptoms of headache, tiredness and irritability**
* **Attend A&E if have early symptoms and nausea, low appetite, cramps, muscle spasm**
* **999 call if convulsion or seizures occur**

The following link is to Society for Endocrinology *Emergency Care Guidance for the Inpatient Management of Cranial Diabetes Insipidus in the Adult Patient*

https://doi.org/10.1530/EC-18-0154

**2)** **You have taken your desmopressin as normal but have then had a large intake of fluid**; this means you will have excess fluid in your system as you will have reduced your urine output with the desmopressin. Having a high fluid intake after taking your desmopressin can lead to a reduced blood sodium level, known as hyponatraemia. This can lead to seizures.

**Hyponatraemia (low sodium)**

This can be graded as mild, moderate or severe.

Correcting hyponatraemia has to be done very carefully to prevent too sudden a rise in blood sodium.

The level of emergency medical attention needed will depend not only on your sodium levels but also on your symptoms at the time.

**Why have I developed hyponatraemia?**

When you take desmopressin this signals to your kidney to reduce or stop losing water from your circulation.

Too high a dose or too much of desmopressin can cause too much water to be kept in the body and this can lower your blood sodium levels.

If you continue to have a strong thirst, and drink to quench the thirst after taking desmopressin, this can also cause over-dilution of the blood and so lower your blood sodium levels.

Other illness can also cause a shift in your fluid balance and result in a drop in sodium levels, especially so if you have vomiting and/or diarrhoea.

**What symptoms may I experience?**

Symptoms can vary and do not always match the level of blood sodium in their severity. So a person with a mild or moderate low blood sodium may have severe symptoms.

Moderate symptoms will include nausea without vomiting, confusion, headaches

Severe symptoms include vomiting, seizures, reduced level of consciousness and possibly cardiac arrest.

**If you have any of these symptoms listed you should seek emergency medical attention**

The following link is to the Society for Endocrinology *Emergency Care Guidance for the Emergency Management of Severe Symptomatic Hyponatraemia in Adult Patients:* <https://doi.org/10.1530/EC-16-0058>

**3)** **You have vomiting (more than once) and/or diarrhoea**. This will affect your fluid balance levels and the levels of sodium and potassium in your blood. It may become difficult for you to keep control of your DI in these circumstances. This is especially important if you take cortisol replacement, as reduced cortisol levels also have an impact on your blood sodium levels. This situation would need you to attend accident and emergency or urgent care department for urgent assessment and stabilisation.

If you have taken extra desmopressin for whatever reason and your urine output has dropped significantly, as long as you are not thirsty and dehydrated, try to limit your fluid intake, and take no further desmopressin until you have symptoms of thirst and an increasing urine output. If your urine output does not increase within 12 hours then seek medical advice.

**SYMPTOMS**

|  |  |  |  |
| --- | --- | --- | --- |
| **Hypernatraemia** | **Mild** | **Moderate** | **Severe** |
|  | * Headache * Fatigue/Lethargy * Nausea * Irritable * Thirst/dry mouth | Mild symptoms, plus   * Confusion * Muscle spasms * Change in skin turgor * Dry | Mild and moderate symptoms, plus   * Increased confusion * Twitching/ myoclonic jerks * Convulsions * Coma/unconsciousness |
| **Action to take ↕** | **Urgent GP/A&E ↕** | **Urgent A&E ↕** | **Urgent A&E/ 999 ↕** |
| **Hyponatraemia** | * Fatigue/Lethargy * Irritable * Headache * Reduced appetite | Mild symptoms, plus   * Weakness/   muscle cramps   * Confusion * Nausea without vomiting | Mild and moderate symptoms, plus   * Increasing confusion * Nausea and vomiting * Convulsions/seizures * Coma/unconsciousness |

**ACTION**

|  |  |  |
| --- | --- | --- |
| **Illness or Situation** | **Action to take** | **Urgent care needed** |
| Heavy cold/blocked nose/sinusitis | Take desmopressin as normal  If using nasal spray, switch to tablet or melt format for duration of illness to ensure full doses received. Maintain fluid intake. | **Yes -** if unable to take desmopressin and unable to maintain fluid intake. |
| Headache, irritable, increasing tiredness, nausea, loss of appetite muscle cramps, confusion, reducing level of consciousness | **Attend A&E** | **Yes - attend A&E urgently, depending on severity of symptoms you may need ambulance transport** |
| Convulsions/seizures | **999** | **Yes - urgent medical care needed** |
| Vomiting/diarrhoea (more than once) | Take desmopressin as normal  Maintain fluid intake, likely to need extra to cover that lost with illness. | **Yes - need to ensure DI is stable.**  **Will need urgent medical attention if D&V severe and continuous or unable to retain desmopressin.** |
| Excess intake of DDAVP (above prescribed doses) | Miss or delay next desmopressin dose.  Limit fluid intake until urine output is restored to normal for you.  Allow symptom ‘breakthrough’ (thirst and excess urine) before taking next desmopressin dose. | **Yes -** if urine output remains low or you develop symptoms listed in Row 2. |

**What about planned surgery or investigations**

* You should let the healthcare team looking after you know that you need desmopressin as a life-preserving replacement therapy.
* It may be helpful to refer them to your endocrine specialist who could provide specific care instruction regarding your DI and management when in hospital.
* You may need to explain to them the importance of having access to both your desmopressin treatment and to fluids. If you are not able to take fluid by mouth then your health care team may need to insert a cannula to provide you with intra venous fluids (a ‘drip’)
* This advice should be followed for any planned surgery, either as day case or inpatient, as fluid balance and needs can change when undergoing anaesthetic.
* It also applies if you are having preparation for bowel investigations, as this generally causes a temporary diarrhoea to clear out the bowel. This can have an adverse effect on your fluid balance.
* Simple procedures that allow you to have normal diet and fluids in the pre- and post- procedure times should not need any adjustment of desmopressin dose.
* If you are unsure in any way contact your endocrine team who can help clarify this for you.

**Further information can be obtained from the links listed below:**

Pituitary Foundation booklet: <https://www.pituitary.org.uk/product/diabetes-insipidus-avp-d-booklet/>

Society for Endocrinology Emergency Care Guidance for the Inpatient Management of Cranial Diabetes Insipidus in the Adult Patient: <https://doi.org/10.1530/EC-18-0154>

Society for Endocrinology Emergency Care Guidance for the Emergency Management of Severe Symptomatic Hyponatraemia in Adult Patients: <https://doi.org/10.1530/EC-16-0058>

**NHS England Stage One: Warning:** Risk of severe harm or death when desmopressin is omitted or delayed in patients with cranial diabetes insipidus <https://www.england.nhs.uk/patientsafety/wp-content/uploads/sites/32/2016/02/psa-desmopressin-080216.pdf>

**This fact sheet provides general information only. All patients are different and if you have any questions, please contact your consultant or GP.**

The Pituitary Foundation in collaboration with The Society for Endocrinology